

**Intergenerational Experiences of Young
Onset Dementia: A Qualitative
Longitudinal Study**

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I started my PhD in October 2012 after fifteen years at home raising my family. To say I was daunted was an understatement; when I did my Master's degree in the early 1990s access to journal articles was via a few box files in the library rather than electronic databases!

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Glossary of terms

Alcohol-related dementia. Sometimes referred to as Korsakoff's syndrome, alcohol-related dementia is caused by a lack of vitamin B1 (thiamine) due to excessive alcohol consumption. Korsakoff's syndrome is nearly always preceded by a condition called Wernicke's encephalopathy, which can be reversed in some cases, preventing permanent brain damage. If untreated, or not treated quickly enough, Korsakoff's syndrome may develop. Short-term memory loss can be severe in Korsakoff's syndrome; people may confabulate, and there can be changes to personality. People with alcohol-related dementias/Korsakoff's syndrome can be treated with thiamine and, with a healthy diet and abstinence from alcohol can prevent further damage to brain tissue.

Alzheimer's disease. First observed by Alois Alzheimer early in the 1900s, Alzheimer's disease is the most common form of dementia, and is characterised by memory loss, communication problems, reasoning difficulties or mood changes. Clinically, brain cells may die as a result of structural damage to the brain in the form of amyloid plaques and neurofibrillary tangles. People with Alzheimer's disease typically have a shortage of acetylcholine in the brain, and there are drugs available for people in the mild to moderate stages of the condition (donepezil hydrochloride, rivastigmine and galantamine) which can maintain the levels of this biochemical, thereby decelerating the progression. Memantine can be used in the moderate to severe stages of Alzheimer's disease to slow cognitive deterioration, but there is little evidence to suggest that it is efficacious in the earlier stages.

Posterior cortical atrophy (PCA). Usually considered to be a rare atypical variant of Alzheimer's disease, PCA causes similar neuropathological damage to brain tissue but occurs initially in the posterior rather than the frontal lobes of the brain. Visual association areas of the brain are predominantly affected in the earlier stages; thus, people with PCA initially present with decline in visual function rather than memory loss.

Typically, they have more insight into their condition and better verbal fluency than people living with Alzheimer's disease in the early stages of the condition (Mendez & Perryman, 2002). As PCA progresses, the neuropathology develops in other areas of the brain causing symptoms more typically associated with Alzheimer's disease, and the decline in visual function continues until blindness occurs.

Semantic dementia. A form of fronto-temporal dementia (FTD), semantic dementia is caused by loss of neural connections and brain tissue in the frontal lobes of the brain, affecting language and vocabulary. People with semantic dementia may forget the meanings of words or may use general categories to describe specific things, for example 'animal' in place of 'giraffe'. As the condition progresses, they may struggle to understand conversations, recognise objects and faces and may start to forget day-to-day events.

Abstract

This thesis presents sociological understandings of processes that occur in intergenerational relationships when one person develops young onset dementia i.e. dementia before the age of 65. While interest in the subjective experience of this condition has increased in recent years, qualitative research has almost exclusively focussed on individuals - those living with the condition, their spousal carers or their children - rather than enmeshed family and friend relationships. In addition, virtually all of the research on this dynamic, unpredictable condition has been cross-sectional and is limited in the extent to which it can capture change as dementia progresses.

To address this limitation in the knowledge base, this study uses a qualitative longitudinal methodology to generate insights into the effect of young onset dementia on intergenerational relationships over time. The research questions this study addresses are: 1) How do people within intergenerational families make sense of young onset dementia over the past, present and future and 2) To what extent and by what processes do people within different generations experience a sense of belonging to the experience of dementia?

Eighteen participants from five intergenerational families where one person had received a diagnosis of young onset dementia were recruited via two third sector service providers. All five families participated in the first wave of interviews and three families were retained throughout the year-long data collection process and were interviewed at months 0, 6 and 12. Data were analysed as unique cases to create compelling, richly textured intergenerational accounts, then brought into conversation with each other through a cross-case generational analysis.

The novel application of a longitudinal sociological perspective in a field dominated by cross-sectional practitioner research has enabled the generation of unique knowledge about how young onset dementia is lived in a broader relational context. Specifically, two generations were less connected to the experience of dementia: parents of people with young onset dementia, who were perceived to have unrealistic expectations about their child's limitations, and grandchildren, who were perceived to have limited awareness

about the condition. Additionally, the concept of transgenerationality, where a grandparent with dementia was perceived to have relocated in a grandchild's generation, has been developed.

The recommendations for policy and practice are that the provision of support should be broadened from the current focus on the carer-cared for dyad to encompass a wider range of interpersonal relationships.

Chapter One: Introduction

About a year ago a buried memory emerged. I remembered being quite a young child, probably about eight or nine years old, listening to my father's tears through a wall on his return from a visit to his parents' house. We children had been shepherded into the back room by my mother, who, when questioned later, said something like my paternal grandfather had 'lost his mind'. I never saw my grandfather again. I have another memory of saying to my mother on the day of my grandfather's funeral that my father did not seem very upset. I cannot remember her exact words, but her implication was that my father was not grieving because my grandfather had died a long time ago. All I recall then is a fleeting moment of confusion, of wondering how someone could have both just died and already been dead for a long time. I imagine some childhood diversion then took my attention and I have no other memory of that time.

At the outset of this thesis, I believed that no-one in my close family had developed dementia but I now feel, as Mauthner and Doucet (2003) suggest, that I was not fully aware of my motivations for choosing this particular study. Hints emerged over time, however. In the early literature-scoping days of my research, for example, the following quote by Harris and Keady (2009) stood out; chiming, as it must have done, with my unconscious memory:

'Dementia touches all members of the family, and in the context of younger people with dementia, perhaps more so and more acutely' (p. 442)

Although my grandfather was older than 65 when he developed dementia, Harris and Keady's allusion to the impact of dementia across whole families resonated with me, particularly in light of my growing awareness that the existing literature focussed almost entirely on the experience of individuals: carers, people living with young onset dementia or the (adult) children of people with dementia. Their statement, then, draws attention to an aspect of the experience of young onset dementia that has been virtually entirely neglected in academic research: the effect of the condition on enmeshed intergenerational relationships. While increasing interest has been shown in the use of

qualitative approaches to develop rich understandings of the experience of living with young onset dementia, there remains a virtual absence of knowledge on the kinds of processes that occur within intergenerational families and friendships when one person develops the condition.

In addition to the individualistic focus of existing research, the current body of knowledge is largely founded on cross-sectional studies. Studying a dynamic, progressive condition using cross-sectional methods is likely to only partially capture the nuances of how people live with and make sense of a progressive condition over time, and basing decisions on service provision to support younger people with dementia and their families on an underdeveloped body of knowledge is clearly problematic. In addition, there is a marked lack of sociological perspectives on young onset dementia (Tolhurst & Kingston, 2013), despite the discipline's long and respected tradition of research into family and personal relationships, identity transitions and the experience of living with chronic illness.

This thesis, therefore, seeks to develop sociological understandings of how generations within a family and friendship network experience young onset dementia over time. Importantly, this research has taken place against the backdrop of increasing public and policy interest in dementia, and a methodology with an explicit temporal and relational stance needed to be selected that had the potential to explore the interplay between social change and individual lives. Qualitative longitudinal (QL) methodology, an approach which has recently enjoyed a resurgence as a means of understanding processes of change and continuity (Holland & Edwards, 2014), has been selected as the most appropriate methodology to generate the insights sought. From a theoretical perspective I have chosen to use the lenses of symbolic interactionism, family practices, belonging and the sociology of personal life to elucidate the meanings that people construct intersubjectively as they experience young onset dementia over time.

Dementia

Dementia is an umbrella term used to describe a range of conditions affecting brain tissue that cause deterioration in cognitive ability, leading to difficulties managing the activities of daily living (Hughes, Louw & Sabat, 2006). Memory, language, speech, emotion, and behaviour are all areas of functioning that can be affected and the trajectory of the condition and rate of decline are unpredictable. Dementia is increasingly being recognised as the foremost global health challenge of our generation (Alzheimer's Disease International, 2015); worldwide, 35.6 million people are thought to be living with the condition, and World Health Organisation projections indicate that this figure is likely to double by 2030 and to be greater than three times as many by 2050 (WHO, 2012). In the UK alone, 850,000 people are thought to be living with dementia (Alzheimer's Society, 2015).

Although dementia is often socially constructed as a condition affecting people in later life (Chaston, 2011), 1 in 20 people with dementia are diagnosed before the age of 65 (Alzheimer's Society, 2015). Dementia in the under 65s is termed '*early onset*' (WHO, 2010, code F00.0*) or '*young onset*' (Sampson, Warren & Rossor, 2004, p.125), and there are thought to be over 42,000 people in the UK living with the condition, although this number is likely to be an underestimate due to misdiagnoses. Although the threshold age of 65 is arbitrary (Davies, Doran & Lerner, 2011), younger people may have a different experience to older people. For instance, there is some evidence to suggest that dementia in younger people progresses more quickly than in people over 65 (Vieira et al., 2013), and socially, people who develop the condition at an earlier stage in the life course are likely to have a different experience (Tolhurst, Bhattacharyya & Kingston, 2012). Younger people are more likely to be working, to have major financial commitments, to have a rare form of the condition, to be raising children or supporting young adult children and to have parents who might need support (Roach, Keady & Bee, 2011).

Positioning the thesis

Young onset dementia, then, is likely to emerge in the context of embedded intergenerational relationships, and while there has been a welcome attempt in recent years to develop qualitative understandings of the lived experience of young onset dementia (Clemerson, Walsh & Isaac, 2014), all but one study has focussed on the perspectives of a single generation, neglecting the impact of the condition on the broader family and friendship context.

Attempting to position the thesis entirely within the young onset dementia body of knowledge, then, would be problematic on at least two counts: there are few empirical studies which my inquiry can be directly related to, and theoretically, there is a dearth of sociological understandings on family relationships in the context of dementia. Although attempts have been made to explicate sociological constructions of dementia, drawing on the work of Foucault and Bourdieu (Davis, 2004; Kontos, 2004), and recent work proposes that people with dementia should be viewed less as autonomous individuals and more as relational selves (Jenkins, Keyes & Strange, 2016), a cogent sociology of dementia has yet to be established (Tolhurst & Kingston, 2013). In light of these areas of inattention, I have broadened the review of the literature to consider insights that have been gained from the sociology of chronic illness. Even within this vast body of work, however, there is a preponderance of individual studies of living with illness focussing on identity transition rather than multiple perspectival studies of the intersubjective family experience (Knafl & Gilliss, 2002; Årestedt, Persson & Benzein, 2014; Bray, Kirk & Callery, 2014), despite a recognition within the field that the occurrence of illness for one person is likely to impact upon other family members (Muhlbauer, 2002; Gregory, 2005).

A further point that needs to be made is that, notwithstanding Conrad's (1990) call a quarter of a century ago for more longitudinal research to be conducted on chronic illness, many of the family studies in this field of knowledge, in common with qualitative young onset dementia research, have adopted a cross-sectional design, providing a retrospective rather than a prospective view of the impact of illness. Yet, as sociologists, we seek knowledge about process and change, and the extent to which cross-sectional studies can provide dynamic insights is restricted. As Conrad notes:

'we are limited by the retrospective interpretations of our respondents... for some reason, qualitative researchers have not shown the staying power necessary for conducting longitudinal qualitative research... we must take temporal notions like career, process and development seriously, and commit ourselves to longitudinal research'
(p. 1258)

A QL methodology has the potential to address this gap in the knowledge base by yielding prospective longitudinal insights into the relational experience of young onset dementia, exploring how lives unfold over time (Neale, Henwood & Holland, 2012) and paying attention to the interweaving of historical, biographical and generational time.

Structure of the thesis

The following chapter, Chapter Two, provides an overview of the sociology of chronic illness literature, describing sociological insights into the lived experience of enduring illness. Chapter Three delineates the contours of the knowledge base of the insider perspective of young onset dementia, providing a focussed critical review of existing qualitative studies and elucidating gaps in the body of knowledge. Chapter Four outlines the theoretical arguments that frame this study, describing the significance of these approaches to generating in-depth understandings of intergenerational experiences of young onset dementia. Chapter Five explicates the rationale for choosing QL methodology and provides a description of the study design, detailing sample recruitment, ethical considerations, the data collection process and analytic strategies.

Chapters Six through to Nine describe the findings of the empirical research, providing a richly textured, particularistic account of each family's response to young onset dementia. Chapter Ten offers cross-contextual understandings by exploring generational patterns within the dataset and discussing findings with reference to theoretical and empirical knowledge bases. Finally, Chapter Eleven draws the body of work together, summarising the key findings and outlining implications for policy, practice and research.

Chapter Two: The Sociology Of Chronic Illness

Introduction

This chapter provides an overview of the sociology of chronic illness body of knowledge, beginning with a brief description of the development of the field over time, detailing the conceptual shift from an 'outsider' to an 'insider' perspective. Subsequently, temporal and relational themes are explored, and tensions and limitations within the field are discussed with a view to creating a context and justification for a sociological study of young onset dementia.

Conceptual development within the sociology of chronic illness

Since the 1950s, when the notion of Parsons' structural-functionalist sick role dominated sociological understandings (Conrad, 1990), there have been pivotal moments in the development of the conceptual frameworks underpinning the sociology of chronic illness (Lawton, 2003). Put simply, Parsons' concept of the sick role relates to the failure of individuals to function according to their usual role capacity, and, as Gerhardt (1989) notes, the sick person comes to occupy '*some kind of niche in the social system*' (p. 15) where they aim to recover with the assistance of the medical profession. Within this framework, the patient, and their illness, is viewed from an 'outsider' perspective, with no attempt to understand the psychosocial aspects of illness from the ill person's point of view.

In the 1960s, the increasing influence of the interpretive paradigm, and more specifically, symbolic interactionism and ethnomethodology (Gerhardt, 1990), led to the development of interest in the 'insider' perspective (Conrad, 1990; Thorne, 1999) which sought to understand the meanings that people ascribe to their experience of chronic illness. From this perspective, illness is viewed neither as a form of deviance from functionalist roles, nor as a group of concrete clinical symptoms, but as a complex lived experience characterised by lifestyle adaptations, identity and relational transformations and biographical adjustments.

This emerging focus found expression in Glaser and Strauss' *Awareness of Dying* (1966) and Goffman's *Asylums* (1968); yet these studies focussed on patients' experiences within institutional settings rather than on the quotidian experience of living with chronic illness. Glaser and Strauss' collection of student essays, published as *Chronic Illness and the Quality of Life* (1975), was the first well-known study to explore the day-to-day experience of life with a chronic illness (Conrad, 1990). However, the publication of Bury's (1982) seminal work on biographical disruption, situated within the symbolic interactionist tradition (Hubbard, Kidd & Kearney, 2010), was perhaps the most significant turning point in the development of the field. Bury's notion of biographical disruption, influenced by Giddens' (1979) notion of critical situations, was conceptualised from his study of people who developed rheumatoid arthritis at a young age. Biographical disruption theorises illness as a disruptive force that destabilises the structures of everyday life, creates asymmetry in relationships and disturbs an individual's consciousness of their body. Ill individuals have to reconstitute their sense of self and biography, reconsider their future, and mobilise resources to adapt to their change of circumstances. As Bury's participants were experiencing a condition usually associated with later life, there are clear parallels between his study population and younger people with dementia.

While biographical disruption has been an extremely influential framework in the field of chronic illness research, there have been several critiques that have questioned the applicability of the concept to the diverse range of illness experiences. Some scholars have suggested that chronic illness is less disruptive in the context of some individuals' lives; Pound, Gompertz and Ebrahim (1998) and Faircloth, Boylstein, Rittman, Young and Gubrium (2004), for instance, suggested that strokes were not necessarily experienced as disruptive in the context of lives already perceived to be difficult. Sanders, Donovan and Dieppe (2002) argued that older people anticipated chronic illness rather than found it disruptive, and Carricaburu and Pierret (1995), in their study of HIV positive men, found that for men who had haemophilia and already led constrained lives, HIV infection reinforced rather than disrupted biographies.

The concept of biographical disruption, then, has faced criticism for its limited applicability to the diverse range of chronic illnesses. In addition, Lawton (2003) has

suggested that under the conditions of post-traditional late modernity, characterised by increasing lifestyle choices and a continual process of biographical appraisal (Giddens, 1991), the reflexive self is constantly being constituted and reconstituted. In this constant state of flux, it may be problematic to view illness as disrupting a stable biography; rather, illness may merely be contributing to the refashioning of an ever-evolving biography. However, her critique may not stand up to scrutiny, for Giddens (1991) also uses the concept of '*fateful moments*' (p. 202) to describe radical events that disrupt the flow of individual biographies in late modernity, with profound existential repercussions for the affected individual and significant ramifications for their closely-connected others. The onset of a progressive, terminal condition such as young onset dementia could potentially be experienced as a fateful moment. Additionally, the concept of biographical disruption has been criticised for being adult-centric (S. Williams, 2000), for underplaying the relationships between social structural factors and chronic illness such as race (Atkin & Ahmad, 2001), class (Pound et al., 1998) and gender (Bendelow, 1993), and for being predicated upon an autonomous individual rather than exploring chronic illness as an experience affecting entwined lives (Monaghan & Gabe, 2015).

Another influential chronic illness scholar within the symbolic interactionist tradition is Charmaz (1983, 1990, 1991, 1995, 2002a, 2002b). Charmaz's focus is the threatening effect of illness on an individual's sense of self-body unity, and the identity transitions that occur as people seek to adapt to their changed situation (1995, 2002a). Identity, to Charmaz, is constituted through a person's continual definition and redefinition of themselves in relation to others and to their social world. Changes to bodily capabilities or appearance affect the identity goals people construct in their purposeful interaction with the world; preferred identities may therefore have to be abandoned in exchange for ones that have greater congruence with their reduced capacity (Charmaz, 1995).

Although like Bury, Charmaz's main interest is the ill person, she does draw attention to the role of significant others, arguing that they may help the ill person to 'pass', or to conceal their illness in social settings in order to maintain a consistent self-presentation (C. Williams, 2000). This role, of the '*alert assistant*' (Charmaz, 1991, p. 69) requires both a vigilance of and a sensitivity to the ill person's needs and a knowledge of how the person may best be helped. The alert assistant may perform emotion work for the cared-

for person (Young et al., 2002) or mediate between the public and private worlds of the individual they support (C. Williams, 2000).

However, positioning the significant other as an alert assistant, or, to use a commonly used term, a carer, assumes an asymmetry in the relationship (Henderson, 2001; O'Connor, 2007; Molyneaux, Butchard, Simpson & Murray, 2011), and, additionally, focuses attention on a single person providing assistance. The majority of chronic illness research focuses either on the unwell individual, or the effects of illness on the 'carer', or their dyadic relationship, neglecting the impact on the wider family (Wilson, 2007; Årestedt et al., 2014; Wolf, 2015). Little consideration, therefore, is given to the dynamic interplay between biographies within families (Carricaburu & Pierret, 1995; Harden, 2005; Bray et al., 2014) even though a family remains the form in which most of us live (Gregory, 2005) and meanings of chronic illness may be embedded in family history (Jowsey, Ward & Gardner, 2013), particularly when the illness may have a genetic link, as can be the case with young onset dementia. Exploring family experiences through the lens of either an individual account, or even a dyadic relationship, may fail to capture the nuances of the interconnectedness of the wider family and friendship network (Wolf, 2015).

Family responses to chronic illness

Since the 1980s much of the sociological research on chronic illness has been conducted within the interpretive paradigm using qualitative methodologies (Thorne et al., 2002) as attempts to understand the meanings ascribed to illness by those living with conditions became a credible endeavour for researchers (Thorne, 1999; S. Williams, 2000).

Quantitative studies which have sought to measure particular concepts, for example, stress and family health outcomes, have been critiqued for decontextualising the lived experience of chronic illness (Thorne, 1999; Boström & Ahlström, 2004).

People's experiences of illness, it has been argued, can only be understood within the unique context of their lives (Atkin & Ahmad, 2001; McNeill et al., 2014), comprising prevailing cultural and familial norms and expectations crucial to the construction of

meanings (Gallo & Knafl, 1998; S. Williams, 2000; Bray et al., 2014). For example, the age of onset of a condition has been viewed as a key mediator of people's experience; Bury and Holme (1991) suggest that people have a '*social clock*' (p. 94) by which they situate their expectations of health and illness within their biographies. However, although illness may be more anticipated in older age (Sanders et al., 2002), where a life is already marked by illness (Faircloth et al., 2004) or in more socio-economically deprived communities (Pound et al., 1998), it is important not to make assumptions that the lives of older or less affluent people will be less disrupted by illness (Wilson, 2007). Ultimately, then, the tension within the field can be considered in terms of underlying epistemological concerns; while Lawton (2003) describes biographical disruption as a '*welcome attempt*' (p. 25) to move from empirical description to abstract theorising, others argue that the concept lacks the sensitivity to explain the uniqueness of particular contexts. This tension must be navigated by researchers wishing to conduct sociological inquiry into the experience of illness. Some key themes emerging from the field will now be described.

Normalisation

The concept of normalising illness within families is commonly reported in the literature (Knafl & Gilliss, 2002). For Knafl, Breitmayer, Gallo and Zoeller (1996), normality within a family was a dominant characteristic within their 'thriving' illness management style. Locock, Ziebland and Dumelow (2009) noted that participating families living with motor neurone disease sought to retain a sense of normality, while the ill mothers in Wilson's (2007) study prioritised a normal life for their children. For Bray et al. (2014), normality was related to biographical continuity, the attempt to retain a coherent flow between past, present and future. Emiliani, Bertocchi, Poti and Palareti (2011) delineated two aspects of normality, the cognitive and emotional processes of maintaining a sense of everyday ordinariness (Prout, Hayes & Gelder, 1999), and the process of integrating and routinising treatment regimens into everyday family practices. Gregory (2005) observed a tension between normality and having to incorporate activities based on medical advice into family routines; however, the quotidian integration of new activities could offer a

new sense of predictability within the family, increasing the ontological security of family members. For younger people with dementia, however, medical treatment regimens are unlikely to have a substantial impact on family practices, since the medications available to reduce the rate of progression of the disease are typically taken only once or twice a day. However, people with dementia may engage in activities which they hope will slow the advancement of dementia such as puzzles and other brain-training exercises (Pipon-Young, Lee, Jones & Guss, 2012).

Creating an '*new sense of normal*' was noted by Hubbard et al. (2010, p. 138) in their study of people with colorectal cancer. They noted that there were two processes of normalisation, either that families make attempts to incorporate the illness into an altered lifestyle, a finding also noted by Clarke-Steffen (1997) and Horner (1998), or that they act to preserve a pre-illness lifestyle through concealing or ignoring illness.

Monaghan and Gabe (2015) argue that processes of normalisation are contingent upon the enacted or anticipated reactions of others; and Jowsey et al. (2013) noted that ill individuals and their families act with agency to manipulate the boundaries of normality and illness so that illness is sometimes revealed to others and sometimes not. However, according to Dewar (2001), creating an appearance of normality is not always possible, and Spirig (2002) observed that attempting to maintain normality may be viewed by health care professionals as a form of denial.

Striving for a normality may therefore be a commonly occurring goal in family life where someone is ill (Locock et al., 2009; Årestedt et al., 2014), but may be fraught with difficulties. Maintaining ordinariness may symbolically serve to support a valued self (Boström & Ahlström, 2004), or may cause internal conflict for individuals (Telford, 2006), but interactions with others are likely to have a powerful influence over the extent to which families can limit the effects of illness on everyday life. How families view the past, present and future is also likely to have a profound impact on their ability to strive for normality.

Temporality

The onset of an unanticipated disease requires a reconstruction of the present and the future (Carricaburu & Pierret, 1995; Lawton, 2003), but also often prompts a reconfiguring of the past (Jowsey et al., 2013). For instance, Pejlert (2001) and Harden (2005) both found that family members presented an idealised view of the ill person before the onset of the disease. Charmaz (1991, 2002) has also argued that ill people refer to their past for a frame of reference with which to interpret the present, and may prefer to inhabit a valued pre-illness identity rather than to construct a less-favoured identity which reflects the restrictions brought about by illness.

Dependent on the nature of the illness, families manage the present in different ways. Årestedt et al. (2014), for instance noted that families adopted a new temporal rhythm, slowing the pace of life and restricting activities, whereas for Locock et al.'s (2009) participants living with a terminal disease, families focussed on planning holidays and cherishing every day. A sense of urgency characterises this more intense focus on the present as people seek to maximise their enjoyment of every remaining moment (Charmaz, 1991).

Reconstructing the future appears to be one means that families adopt to take control of the illness (Carricaburu & Pierret, 1995; Harden, 2005), although others reportedly dismiss thoughts of the future (Boström & Ahlström, 2004). For Charmaz (1991), there are four meanings of the future that ill people can locate their selves within: the dreaded future, the improved future, the taken-for-granted future and the everlasting future. Those who dread the future, she argues, feel trapped in a sense of doom, whereas in the improved future, others expect to become their preferred self. In the taken-for-granted future, people's view of reality lies within future horizons than in the past or the present. In the everlasting future, people turn their focus to how their identity might last beyond death, by leaving some form of legacy. Although one might assume that younger people with dementia are unlikely to anticipate an improved future, it may be that a preferred identity, such as a dementia activist, may emerge (Bartlett, 2014).

Protection and secrecy

Managing an ongoing illness in a family context is undoubtedly a complex process (Larson, 1998; Rallison & Raffin-Bouchal, 2013). The shifting balance between dependence and interdependence (Chattoo & Ahmad, 2008) can challenge family members' beliefs both about health and illness and about their entwined lives and relationships (Årestedt et al., 2014). Family norms and expectations, refined and negotiated over time (Gregory, 2005), may be challenged and reciprocity compromised as a result of changing abilities (Dewar, 2001). Protection is one strategy that ill individuals may adopt as they seek to shield significant others from their own anxiety, shock or future fears (Charmaz, 1991; Carricaburu & Pierret, 1995; Dewar, 2001; Weingarten, 2013). Protecting family members may lead to the effects of the illness being hidden, and secrecy can become a key element of managing everyday life (Carricaburu & Pierret, 1995) as people attempt to avoid guilt resulting from distressing their family members (Atkin & Ahmad, 2001).

The processes by which information about a condition are mediated within families appears to be an under-explored area. Although Årestedt et al. (2014) found that seeking and sharing information as a family practice can strengthen family relationships, and Emiliani et al. (2011) found that young children were often not informed about family illness, less attention has been paid to the general processes that underpin the flows of information within families (Smart, 2011).

Ill people may also seek to protect themselves, by avoiding situations that render their losses apparent to themselves or to significant others (Dewar, 2001). According to Boström and Ahlström (2004), interaction with seemingly healthy others can induce emotional strain as personal limitations become more obvious through comparison. In contrast, support groups can be seen as a collective experience of illness (Tolhurst & Kingston, 2013), as a way to become empowered (Jowsey et al., 2013), gain mutual understanding and support (Telford, 2006), a place to share information (Faircloth et al., 2004) and a means of lessening the strain on family members (Dewar, 2001).

Communal coping

Wolf (2015) in her study of breast cancer, found that communal coping, was not highly visible within families and that the illness was viewed more as a disruption to the ill individual's biography; the communal coping that did occur was more likely to be between spousal pairs rather than from adult children. Similarly, Muraco & Fredriksen-Goldsen (2014) found that norms of obligation were more deeply felt in spousal relationships rather than among the wider network of family or friends. Relationships with friends seemed more fragile; conflict, Muraco & Fredriksen-Goldsen (2014) found, had the potential to strengthen spousal relationships but was viewed as detrimental in friendship relationships.

Limitations within the field

Sociological understandings of the effects of illness on families have done much to illuminate the daily lives of people experiencing chronic conditions. However, there are limitations in the body of knowledge. Studies of terminal disease are relatively few (Lawton, 2003), and there is a preponderance of studies of people without cognitive impairment or verbal difficulties; as Thorne et al. (2002) state:

'diseases that influence verbal communication... are disproportionately unpopular research topics... qualitative researchers might prefer to conduct studies with verbal, articulate and competent adults' (p. 444)

Therefore, as useful as the insights from this body of knowledge are, there are particular challenges in the context of dementia (La Fontaine & Oyebode, 2014) which may compound some of the processes described. Normalisation, for example, may be more difficult where there are behavioural changes, and temporal understandings may be challenged as a person's connection with their past, present and future becomes destabilised by cognitive impairment. Additionally, while stigma is a well-discussed phenomenon in illness, it may be more acute with respect to dementia (Alzheimer's Disease International, 2012) and may affect processes of protection and secrecy within family and friendship networks.

Additionally, the field remains dominated by a focus on individual biographies and rarely attends to the influence of relational processes in shaping responses to illness (Bray et al., 2014). The body of research that has attempted to explore entwined intergenerational biographies is both small and relatively homogeneous, being dominated by studies of parents of children with cancer (Knafl & Gilliss, 2002). In addition, despite Conrad's (1990) call for longitudinal research, cross-sectional studies continue to dominate the field.

Summary

This chapter has provided an overview of the sociology of chronic illness literature, describing the shift from the 'outsider' to the 'insider' perspective and highlighting epistemological debates around the influential concept of biographical disruption (Bury, 1982). Key themes such as normalisation, temporality and secrecy have been discussed and limitations within the field exposed, demonstrating the opportunity to extend the knowledge base with research that explores intergenerational responses to a terminal condition such as young onset dementia.

The existing body of literature on the insider perspective of young onset dementia will now be described and critiqued to outline the contours of the existing knowledge base and to elucidate the gaps in understanding that this thesis addresses.

Chapter Three: Young Onset Dementia Literature Review

Introduction

Positioning this thesis in relation to the existing young onset dementia research is challenging due to the lack of sociological studies and the dearth of family or intergenerational studies of the experience of living with the condition. The majority of studies within the interpretivist paradigm focus on a single generational group such as people living with young onset dementia, their carers or their children; explorations of the effect of the condition on embedded relationships are, therefore, virtually absent from the body of literature.

Nevertheless, the existing qualitative studies have provided important insights into how individuals experience young onset dementia. This chapter provides a focussed review of the current knowledge base, identifying limitations and exploring themes that encapsulate various dimensions of the experience including: receiving and disclosing the diagnosis, accessing information and services, the effect on family relationships, and experiencing loss. Prior to the focussed literature review there is a brief historical overview of the development of the knowledge base.

The development of the young onset dementia knowledge base

In the early years research into young onset dementia was dominated by biomedical approaches focusing on pathological processes and clinical features of the disease (e.g. Nott & Fleminger, 1975; Liston, 1979; Horner, Heyman, Dawson & Rogers, 1988). Famously, Alois Alzheimer's discovery in the early 1900s of the characteristic amyloid plaques and neurofibrillary tangles was made during a postmortem on the brain of a woman in her fifties. Indeed, Alzheimer's disease was originally understood to be a form of dementia particular to younger people, expanding in the 1970s to include diagnoses of dementia in older people (Kitwood, 1997). With increasing numbers of recorded cases, Alzheimer's disease became a major focus of biomedical studies in the 1970s and 1980s and research subsequently expanded to include other dementias found in younger

people, such as frontotemporal degeneration, Lewy bodies dementia and prion diseases (Greicius, Geschwind & Miller, 2002).

In the 1980s and 1990s, the developing sociological interest in the subjective experience of chronic illness, discussed in previous chapters, may have influenced the emergence of a new paradigm of research on younger people with dementia: the collection and analysis of qualitative data on the 'insider' perspective. Additionally, the groundbreaking work of Kitwood (1993, 1997), and simultaneous developments elsewhere in the world (Sabat & Harré, 1992) were challenging the medical view of the person with dementia as an entity with neuropathology, seeking to locate the person, rather than the condition, at the heart of dementia care. With policy agendas shifting towards recognition of the value of user consultation (e.g. NHS and Community Care Act, 1990), and disability research rejecting conceptualisations of individual pathology, problematisation of disability and pitiable personal tragedy (Stone & Priestly, 1996), the beginnings of a more inclusive and sensitive person-centred paradigm of dementia began to form (Clarke & Keady, 2002), and the focus on understanding the experience of dementia from those living with the condition began to develop.

However, ripples of the biomedical influence can be ascertained in the earlier social research studies of young onset dementia. Newens, Forster and Kay (1995), for instance, refer to the people with dementia in their study as 'cases', while in the same year, Delany and Rosenvinge describe their participants as 'sufferers' and focus their data collection on the cognitive and behavioural disabilities of the people with dementia rather than exploring an 'insider' view of the condition.

Another influence on the young onset dementia research agenda was the emergence and politicisation of the term 'carer'. Heron (1998) notes that 'carer' appeared in the late 1970s as a way to describe a person, usually a family member, who provides unpaid care to someone who is unable to manage on her or his own. Welfare benefits such as the Invalid Care Allowance (1976) and Home Responsibilities Protection (1978), offering financial support to informal carers were created, and support groups, such as the Association of Carers (established in 1981), began to form.

Feminist academics also started to turn their gaze towards informal caring, with Hicks (1988) and Finch (1989) both developing a scholarly interest in this area of research. Around the same time, Pearlin, Mullan, Semple & Skaff (1990) and Rolland (1984, 1987) were developing, respectively, the stress process model of caregiving and the family-systems illness conceptual model, theoretical constructs that continue to influence empirical studies on informal caring.

This increasing awareness and recognition of the role of family members and friends providing care appears to have had a strong influence on the research focus within the young onset dementia knowledge base. One of the earliest social research studies on young onset dementia (Sperlinger & Furst, 1994) used a qualitative methodology to develop understandings of carers' service experiences. The focus on carers of younger people with dementia broadened to include quantitative designs, and it forms a strong strand of research that persists to the present day (Luscombe, Brodaty & Freeth, 1998; Williams, Dearden & Cameron, 2001; Kaiser & Panegyres, 2007; Allen, Oyebode & Allen, 2009; Rosness, Mjørud & Engedal, 2011; Bakker et al., 2012; Ducharme, Kergoat, Antoine, Pasquier & Coulombe, 2013).

Studies that attempted to explore the perspectives of younger people with dementia themselves are far fewer in number, and, as previously mentioned, those studies that did include younger people with dementia tended to focus on their clinical features rather than their lived experiences (Delany & Rosenvinge, 1995; Newens et al., 1995). Cox and Keady's (1999) edited volume, while focusing predominantly on service planning and practice, was perhaps the first to include insights gained from qualitative research encounters with younger people with dementia (Killick, 1999). Freyne, Kidd, Coen and Lawlor's (1999) much-cited study published in the same year collected data (Mini-Mental State Examination, Baumgarten Dementia Behaviour Disturbance Scale) from younger and older people with dementia but only to correlate these variables with measurements of carer burden (Zarit Burden Interview, Social Support Appraisals Scale and General Health Questionnaire-30) to ascertain whether carers of younger sufferers (*sic*) had a higher level of burden. Similar studies also compared carers of younger and older people (Arai, Matsumoto, Ikeda & Arai, 2007) or carers of people with fronto-temporal dementia compared to carers of people with Alzheimer's disease (Nicolaou, Egan, Gasson & Kane,

2010). While studies of this nature may have importance for policy (Bury, 1991), the extent to which they have explanatory power or are able to create understandings of the complexity of experience is extremely limited. More importantly, they problematise younger people with dementia, silencing their voices and objectifying them as a cause of burden.

This construction of the younger person with dementia as a problem or burden, and the virtual absence of their accounts in the literature, was observed by Beattie, Daker-White, Gilliard and Means (2002). In their review of seventy four papers, they identified only five that reported the experiences of younger people with dementia. Indeed, despite Cotrell and Schultz's (1993) landmark work in the general field of dementia, which drew attention to the impoverished knowledge base forged by researching the condition without including the perspectives of those living with it, studies focusing on understanding the subjective experience of young onset dementia did not gain momentum until early in the 21st century.

Two early examples of this approach are Beattie, Daker-White, Gilliard and Means (2004) and Harris (2004). Both conducted qualitative interviews with younger people with dementia in the UK and the USA respectively, using a grounded theory approach to the data collection and analysis. Beattie et al.'s (2004) study also included a postal survey of service commissioners and providers, and the practice orientation of the researchers can be perceived in the themes generated, for instance, concerns about age-appropriate services and risk and danger issues. Harris's (2004) analysis has a broader and more dynamic focus, constructing themes such as family relational changes, changes in selfhood and marginalisation. However, the extent to which they contribute to theoretical development is limited.

This empirical emphasis within the production of knowledge is a common thread in this field of literature, with only the most recent studies starting to address theoretical concerns, albeit often in a limited way. Allen et al. (2009), Oyebode, Bradley and Allen (2013), Pipon-Young et al. (2012), Roach et al. (2013), Tolhurst and Kingston (2013), Clemerson et al. (2014) and Hutchinson et al. (2014) appear to be the only studies to offer theoretical considerations. This apparent weakness in the research-theory link does

the knowledge base on young onset dementia a disservice, potentially relegating some of the studies to '*islands of knowledge*' (Walsh & Downe, 2005, p.205).

The largely atheoretical nature of the literature has created, over time, a poorly integrated knowledge base on the experience of younger onset dementia. Conceptual confusion is also present. For example, while there has been recent interest in selfhood in the context of younger onset dementia (Tolhurst et al., 2012), influenced by the work of Sabat and Harré (1992), attempts to define the concept have been minimal. Furthermore, the concepts of self, selfhood, personhood and self-identity are often used interchangeably and with no reference to classical social psychological theories of self, such as those propounded by Mead (1934) or Goffman (1959). This inattention to the delineation of conceptual elements creates ambiguity within the body of literature.

A further weakness in the knowledge base is the lack of intergenerational studies that explore the condition in the context of entwined biographies. Virtually all of the qualitative studies have focussed either on the primary carer or the person with dementia. More recently, studies have explored the experiences of children and young adults (Allen et al., 2009; Svanberg, Stott & Spector, 2010; Millenaar et al., 2013; Barca, Thorsen, Engedal, Haugen & Johannessen, 2014; Hutchinson et al., 2014). However, despite Harris and Keady's (2009) suggestion cited at the beginning of this thesis that young onset dementia affects all members of a family, only one study has been located that has attempted to explore familial experience of young onset dementia (Roach et al., 2013). While this is a clear gap in the knowledge base, any study involving families, for the purposes of conceptual clarity, needs to be framed by theories of family and family relationships. While there are many strengths to Roach et al.'s (2013) study, a theoretical framework was distinctly lacking in their approach.

In summary, the body of knowledge emerging from social research of young onset dementia has undergone significant developments over time. From the dominant initial focus on aggregated data from quantitative studies underpinned by positivistic orientations, exploring correlations between variables, the main shift has been towards exploring insider understandings of the complexities of living with young onset dementia.

A lack of theoretical development and areas of conceptual ambiguity have been identified as key weaknesses in the field.

Focussed literature review

This section provides an in-depth critical review of qualitative social research studies of young onset dementia, creating an analysis and synthesis of the studies that are most relevant to the empirical research being conducted for this doctoral study.

While not in itself a meta-study, the review will be guided by the principles outlined by Paterson, Thorne, Canam and Jillings (2001) in *Meta-study of Qualitative Health Research*, who suggest that merely synthesising data from studies is inadequate. Developing comprehensive understandings of phenomena, they suggest, necessitates scrutiny not only of the findings, but also of the theoretical, methodological and sociocultural factors that have impinged upon and shaped the production of knowledge. The synthesis will, therefore, draw together these analytic strands to construct an interpretation of the knowledge base that will provide a context for the doctoral research.

Literature search strategy

While there is a body of quantitative research exploring variables such as carer burden in young onset dementia (e.g. Rosness et al., 2008; Nicolaou et al., 2010), this review will focus on qualitative studies that have direct relevance to this doctoral empirical study. A comprehensive search strategy comprising electronic database searches and journal and author searches was developed in a determined attempt to access all relevant literature and to verify gaps in the knowledge base. In addition, Zetoc alerts were created for key journals and authors to attempt to identify recently published literature. Details of the search strategy can be located in Appendix A. Inclusion and exclusion criteria were developed and refined as the search progressed and are as follows:

Inclusion criteria:

- Qualitative studies on the experience of young onset dementia including journal articles and grey literature (no date restriction)
- Mixed methods studies on the experience of young onset dementia with a substantive focus on qualitative data
- English language

Exclusion criteria:

- Medical studies, including genetic research, medication trials, articles on prevention, epidemiology studies
- Quantitative studies (however, mixed methods, which may potentially have useful qualitative data were not excluded)
- Studies of intellectual disability and dementia (reflecting the exclusion criteria for the empirical study)
- Qualitative studies of staff/ professional experiences and perceptions
- Studies including nursing home residents (the empirical study is restricted to people living in the community)
- Studies on end-of-life care (the focus is experiences of living with dementia rather than palliative care)
- Methodology papers
- Theses (due to the expense of obtaining full theses)
- Non-English publications (due to the expense of translating into English)

The search retrieved a total of 18 studies published between 2004 and 2014 that will be synthesised for the literature review.

Overview of the selected studies

The 18 studies selected for this critical review are international with the majority from the United Kingdom: UK (9), Netherlands (2), USA (1), UK/USA (1), Ireland (1), Australia

(1), Canada (1) and Norway (2). The studies were published in the following journals: Dementia (6), American Journal of Alzheimer's Disease and Other Dementias (2), Aging and Mental Health (2), Ageing and Society (1), British Journal of Community Nursing (1), Clinical Genetics (1), Health and Social Care in the Community (1), International Psychogeriatrics (2), Qualitative Health Research (1) and Social Work in Mental Health (1).

The studies can be grouped into four categories according to the study samples. For instance, some explore solely the experiences of the younger person with dementia (5), while others focus on the children or adult children of younger people with dementia (6), carers or spouses (5), family constructions including the person who lives with younger onset dementia (1) and one study (Harris & Keady, 2009) combines the data from carers in the UK with data from unrelated younger people with dementia in the USA. Since the data in this paper were taken from a study about which an article on the younger people with dementia was already published (Harris, 2004), the data from the carers in this study will be added to the section on carers' experiences of younger onset dementia, bringing a total of six papers in that section.

In terms of the methodologies selected for these studies, grounded theory was the most frequently adopted, with five studies explicitly using grounded theory methodology, and three guided by the principles or containing elements of grounded theory. Three studies used interpretative phenomenological analysis, one was guided by the principles of phenomenology, one had an action research design, one was biographical narrative, one was a single case study and three appeared to adopt a generic qualitative stance.

Of the 18 studies, 15 were cross-sectional and only three had longitudinal designs. A table demonstrating key features of the studies can be located in Appendix B.

Ethical considerations

Not all reviews of qualitative accounts take into consideration the ethical aspects of the research that has been conducted. For example, Sandelowski and Barroso's (2003) framework for critiquing qualitative studies pays very little attention to the ethical stance of the research. However, Paterson et al. (2001) note the importance of assessing the

ethical rigour of studies, as the quality of the data collected in qualitative research is contingent upon respectful interaction with participants and assurances of confidentiality and data protection. Furthermore, the importance of ethical rigour is heightened when the research involves people with cognitive impairments from whom attaining informed consent can be a complex undertaking. Research studies involving people with dementia, should, therefore, detail the dual processes of obtaining the participants' consent and creating a '*safe context*' (Pratt, 2002, p. 165) for the research encounters to take place.

Descriptions of ethical considerations in all of the included studies are brief, perhaps indicating editorial preferences, and it is therefore difficult to conduct a thorough assessment of ethical rigour. Ethical approval was granted for all studies, and some researchers, for example Roach et al., (2013) discuss using Dewing's (2007) model of process consent in research with younger people with dementia. There is no discussion of researcher reflexivity in any of the papers which might have convinced the reader that the relationship between their personal and social location and the production of knowledge had been carefully considered. This omission may again be due to the prevailing editorial culture at the time of submission; yet reflexivity is a crucial aspect of qualitative inquiry that enables readers to consider the researcher's influences on knowledge production (Etherington, 2004).

Structure of the review

Creating a cogent structure to review this complex body of literature has been challenging. In order to bring clarity, the key features of the individual studies within each category will be described. These sections will then be followed by a critique of the theoretical, methodological and ethical aspects of the entire group of studies. A synthesis of the salient findings then creates an opportunity to compare and contrast the perspectives of different categories of participants on the key themes arising from the studies. Finally, drawing the theoretical, methodological and empirical aspects of the studies together will demonstrate the contours of the existing knowledge base and will highlight the gaps in the knowledge base.

Studies on younger people with dementia

The five studies focussing solely on the younger person with dementia are Beattie et al. (2004), Harris (2004), Johannessen and Möller (2011), Pison-Young et al. (2012) and Clemerson et al. (2014). The first three of these adopted a grounded theory approach while Clemerson et al. (2014) used interpretive phenomenological analysis, and Pison-Young et al. (2012) chose an action research design, and is the only longitudinal study in this group.

There is a clear focus in all of these studies on developing understandings of the experiences of younger people with dementia, and in trying to assess the implications for practice. Harris (2004), for instance, in her American study, attempts to answer the question of whether younger people with dementia have a different experience to older people with the condition, and whether it is necessary to create age-specific services or policies for younger people. Beattie et al.'s (2004) research was part of a larger project looking at service provision and therefore focussed more specifically on services and less on day-to-day experiences of the condition, contrasting slightly with Johannessen and Möller's (2011) Norwegian study and Clemerson et al.'s (2014) UK study which both focus primarily on gaining greater understandings of the experiences of young people with dementia. Pison-Young et al.'s (2012) study, described by them as emancipatory, acknowledged the need to include younger people with dementia in research and service development and aimed to collaboratively identify and instigate a change. However, the extent to which it has a truly emancipatory design can be questioned, as the participants did not appear to have any influence on the aims of the study which would normally would be seen as a key feature of this type of design (French & Swain, 1997). All the studies drew on a wide range of existing literature to create the contexts for their research study.

The studies involved individual interviews with younger people with dementia, whilst some also used focus groups (Harris, 2004; Pison-Young et al., 2012) and online interviews (Harris, 2004). The sample sizes ranged from eight (Pison-Young et al., 2012; Clemerson et al., 2014) to twenty-three (Harris, 2004), with participants being recruited from NHS services (Clemerson et al., 2014), specialist and non-specialist day centres in

the UK (Beattie et al., 2004), a chapter of the Alzheimer's Association and a self-help internet support group in the USA (Harris, 2004), old age psychiatric services and memory clinics in Norway (Johannessen & Möller, 2011) and via clinicians in an NHS trust (Pipon-Young et al., 2012).

Studies of children of younger people with dementia

A small but growing international body of research has focussed on exploring the experiences of children of younger people with dementia (Gelman & Greer, 2011). Six recent qualitative studies that have attempted to create in-depth understandings of the experiences of children of people with young onset dementia have been identified. These are: Forrest Keenan, Miedzybrodzka, van Teijlingen, McKee and Simpson, (2007), Allen et al. (2009), Svanberg et al. (2010), Millenaar et al. (2013), Barca et al. (2014) and Hutchinson et al. (2014). Forrest Keenan et al.'s (2007) Scottish study focuses specifically on young people whose parents have Huntington's disease whereas the parents of the children in the other two UK studies (Allen et al., 2009; Svanberg et al. 2010) and in the Norwegian study (Barca et al., 2014) had a range of diagnoses. The diagnoses of the parents were not stated in either Millenaar et al.'s (2013) Netherlands study or Hutchinson et al.'s (2014) Australian study.

Sample sizes ranged from 12 to 33, and for five of the six studies the mean age of participants is indicative of a largely adult rather than child or adolescent sample (mean age range 19-24 years). In contrast, Svanberg et al. (2010) recruited a younger sample within the range of 11-17 years (mean age 14.6 years).

Studies of carers of people with young onset dementia

Six studies will be briefly described in this section. These are Harris and Keady (2009), Bakker et al. (2010), Lockeridge and Simpson (2012), Oyebode et al. (2013), Ducharme et al. (2013) and Flynn and Mulcahy (2013). From a methodological perspective, this collection of studies is relatively heterogeneous; grounded theory, interpretative

phenomenological analysis (IPA), phenomenological influence, single case study and descriptive qualitative methodology were all utilised in the construction of knowledge on carers' experiences of young onset dementia.

With the exception of Bakker et al.'s (2010) Netherlands research which consisted of two data collection points a year apart, all of these studies have a cross-sectional design, and have a broad focus of trying to understand the experience of caring for someone with young onset dementia. Harris and Keady (2009) are more specific, aiming to explore carer selfhood and identity, while Lockeridge and Simpson (2012)'s interest lies in coping strategies adopted by carers. Bakker et al. (2010) aimed to explore a carer's experiences of the process of transition to residential care.

All but one of the studies have opted for a descriptive approach, aiming to develop insights into the perspectives of the young people, whereas Svanberg et al. (2010) have included a comparative element, trying to gain an understanding of how young carers of people with young onset dementia differ from other young carers.

Study of families experiencing young onset dementia

The final study to be reviewed is the only piece of research identified that attempts to gain an understanding of how families respond to young onset dementia over time (Roach et al., 2013). Roach et al.'s study includes the person with dementia and adopts a narrative biographical approach with five family constructions, aiming to explore the families' experiences of living with young onset dementia. Although intending to capture an intergenerational response to young onset dementia, three of the five family constructions were solely spousal. The other two were a wife, husband and daughter, and a wife, husband, brother and uncle. Each family had several interviews over a time period lasting 12 to 15 months. In addition the families were given scrapbooks to complete to enable the co-construction of family biographies. There were no children or young people in the study; the 13 participants were aged between 32 and 76 years old.

Having briefly delineated different categories of studies in an attempt to bring clarity to a faceted body of knowledge, the research will now be reviewed as an entire body of

literature. In keeping with Paterson et al.'s (2001) approach of considering the empirical data in the context of the methodological and theoretical components of the research process, attention will now turn to explicating and critiquing the perspectives underpinning the researchers' efforts to produce experiential knowledge of young onset dementia.

Methodological aspects

As previously noted, five of the 18 studies adopted a grounded theory methodology while a further three had been guided by the principles of grounded theory. As a methodology, Barnett-Page and Thomas (2009), using Spencer, Ritchie, Lewis and Dillon's (2003) framework, have suggested that grounded theory is underpinned by an objective idealist ontology, i.e. the stance that there is a world of collectively shared understandings that is expressed through focussing on cross-contextual commonalities rather than discrepancies.

Grounded theory, devised originally by Glaser and Strauss (1967), has had a hugely significant influence on qualitative health research (Green & Thorogood, 2009). As a systematic means of creating richly textured theory from empirical worlds, grounded theory can be an ideal methodological choice for developing understandings about phenomena about which there is little prior knowledge. Therefore, it holds great potential as a means of generating knowledge and theory about the experience of young onset dementia.

All the grounded theory studies in this review described constructing topic guides for the interviews based on the existing literature, apart from Johannessen and Möller (2011) who did not state how their topic guide was created. The completion of a literature review in advance of data collection is somewhat contentious in grounded theory; many researchers argue that the review of extant literature follows, rather than precedes, the generation of theory (McKenna, 1997). However, the extent to which the authors of the selected studies adhere to the tenets of grounded theory seems to vary. For instance, Beattie et al. (2004) and Barca et al. (2014) state that they use the principles of grounded

theory, or, in the latter case, a 'modified' form of grounded theory, rather than aligning themselves to one particular variant. In addition, theoretical sampling (the process of selecting participants to inform the continually developing theory), one of the hallmarks of grounded theory (Cutcliffe, 2000), does not appear to have been part of any of the grounded theory studies.

A key criticism of this collection of grounded theory studies is that they do not achieve the aims of a grounded theory methodology, notably the creation of theoretical constructs abstracted from the data. All of the studies have produced lists of themes, but, in general, with the exception of Allen et al., (2009) little effort has been made to move beyond the empirical to the theoretical level. Johannessen and Möller (2011) argue that they created a '*model of knowledge*' (p. 413) yet neither explicate the model in any depth nor delineate a theoretical construct created by the research. The methodological integrity of the studies may therefore be brought into question: it is difficult to ascertain what these purportedly grounded theory studies have offered that a generic qualitative approach would not have done. Action research, used by Pipon-Young et al. (2012), is founded on a critical realist stance (Johnson & Duberley, 2000) and focuses on the mechanisms through which social structures are mediated through human perception and interpretation. According to Spencer et al. (2003), objective idealism and critical realism occupy adjacent positions on the realist-idealist continuum and therefore, in an epistemological sense are not hugely dissimilar, with both containing subjective and objective elements. Indeed, Pipon-Young et al. (2012) used Corbin and Strauss's (2008) grounded theory techniques to analyse the data collected from the semi-structured interviews conducted during the first phase of the study.

In contrast to grounded theory, which focuses on abstracting subjective experience, the emphasis of phenomenology is, according to Suddaby (2006), the nuances and complexities of the lived experience of participants. In this collection of studies, one piece of research, (Ducharme et al., 2013) applied the principles of phenomenology to the creation of knowledge about the lived experience of twelve Canadian spouse caregivers of young people with dementia. Norlyk and Harder (2010), have identified several grounds for criticism of phenomenological studies including the lack of articulation of the underpinning philosophy, and the focus on subjective experiences rather than the

essence of the phenomenon. These shortcomings are evident in Ducharme et al.'s (2013) study; there is no exposition of the phenomenological underpinnings of the study and the findings are presented as a list of experiences rather than a description of the essence of a phenomenon.

Interpretative phenomenological analysis (IPA) is perhaps best described as a subjective idealist approach to knowledge generation. With its roots in phenomenology and symbolic interactionism, IPA is a strongly idiographic methodology used predominantly in psychological research to gain understandings of how people ascribe meaning to their experiences (Biggerstaff & Thompson, 2008). The three studies to use this methodology, Lockeridge and Simpson (2012), Oyeboode et al. (2013) and Clemerson et al. (2014) appear to have been conducted in accordance with IPA approaches to data collection and analysis.

While all the studies in the collection could be described having an interpretivist stance, there are positivistic elements in the knowledge base; for instance, the case study of a carer living in the Netherlands offered by Bakker et al. (2010), is part of a much larger mixed methods study and includes some quantitative psychometric measurements. Similarly, Svanberg et al.'s (2010) study, incorporated three quantitative measures (Recent Mood and Feelings questionnaire, Zarit Burden Interview (Short) and Resilience scale) in their grounded theory methodology as a means of triangulating the qualitative data. Svanberg et al.'s use of triangulation, and the implicit quest for verification through inter-rater reliability in Millenaar et al.'s (2013) Dutch study of children of younger people with dementia, are demonstrative of positivistic inclinations in this knowledge base (Johnson, 1999; Green & Thorogood, 2009).

Finally, three studies (Flynn & Mulcahy, 2013; Millenaar et al., 2013; Hutchinson et al., 2014) seem to have adopted a generic qualitative design.

Longitudinal and cross-sectional designs

As stated previously only three of the 18 studies have a longitudinal design. Bakker et al.'s (2010) case study, Pilon-Young et al.'s (2012) action research design, and Roach et al.'s

(2013) biographical narrative study were all conducted over time. However, Bakker et al.'s study only involved two data collection points, a year apart, which may not have been sensitive enough to capture change. Pipon-Young et al. (2012) utilised a three-phase longitudinal design. However, the purpose of this aspect of the study was not to explore changes and continuities in experiences of young onset dementia over time, but to utilise the look-think-act model to use the findings from the first phase of data collection to inform the development of an information leaflet for younger people with dementia. Of the three longitudinal designs, Roach et al.'s (2013) study is arguably the only research that could effectively capture experiential change over time.

The other 15 studies were cross-sectional, and, as Conrad (1990), Harris (2004) and Allen et al. (2009) acknowledge, there are inherent limitations in trying to understand a dynamic process using a cross-sectional design. A longitudinal approach would more fully illuminate transitional processes over time (Neale, 2012).

Ethical considerations

All the studies gained ethical approval, and all the participants were reported to have provided either written or verbal consent. However, there is no description about how the researchers sought to enable their participants to feel comfortable, respected and appreciated. Johannessen and Möller (2011) noted that some of their participants were unsure that they had been given a diagnosis of dementia, and they did not discuss how they, as researchers, dealt with this uncertainty during the interview. There is a growing body of literature on ethical and methodological aspects of conducting research with people with dementia (e.g. McKillop & Wilkinson, 2004; Hellström et al., 2007), and while these particular commentaries would not have been available to the earlier studies, the reference lists for the five studies solely researching younger people with dementia appear to contain only two references of similar material (Clarke & Keady, 2002; Dewing, 2007). Due to the lack of detail, it is impossible to ascertain whether the ethical approaches of the researchers had any impact on the quality of the data.

Roach et al. (2013), in their biographical narrative study of families state that they have adopted Dewing's (2007) model of process consent by obtaining consent at each research encounter, and being prepared to repeat information about the study when appropriate. There are, however, other elements to the process consent model which include being aware of and responsive to signs of well- and ill-being, which are not referred to in the article. Network confidentiality is a key aspect of research with families (Maclean & Harden, 2012) yet this aspect of confidentiality is not discussed, and it is unclear whether the participants were interviewed separately or together, and what impact this might have had on the production of knowledge.

Enabling children and young people to engage in research is clearly important to gain understandings of phenomena from their perspective. However, there are ethical issues to consider. In the UK a young person with mental capacity can consent to research from the age of sixteen years old (Allmark, 2002). Under the age of sixteen, consent is also required from parents or guardians and the researcher must make every effort to provide age-appropriate project information for the children to enable an informed decision. In addition, during interviews, researchers must be cognisant of the generational power imbalance and must ensure that children feel empowered to refuse to answer questions or to withdraw completely from the research process.

Although the details of ethical procedures undertaken are brief, all the researchers described gaining written consent from the participants, and in cases where the child was under the age of sixteen, from their parents as well. Some researchers (Svanberg et al., 2010; Hutchinson et al., 2014) anticipated the possible emotional impact of the young people's involvement in the research and discussed support options with the participants and parents, providing a list of contact numbers of local services. From the limited information available, due consideration appears to have been made of the ethical aspects of research involving children.

Sampling strategies

The majority of studies accessed participants via statutory or voluntary services. While this is an understandable strategy, those not in receipt of formal support may have unique experiences that would not be illuminated by these research designs. As noted earlier, there was no evidence of theoretical sampling in the grounded theory studies, casting doubt on the methodological robustness of these studies.

Grandchildren, parents or friends of young people with dementia were not included in any of these studies; therefore there is an absence of knowledge of the impact of young onset dementia on the experiences of those groups.

Analytic strategies

Consistent with the methodology, some of the grounded theory studies used constant comparative analytic techniques (Beattie et al., 2004; Johannessen & Möller, 2011) during their data analysis. Harris's (2004) description of her approach to the data sounds more akin to a generic thematic analysis than constant comparative analysis, which casts doubt on the extent to which it can be considered to be a rigorous grounded theory study. Moreover, there is a slight quantitative aspect to her analysis; for a theme to be judged as major it had to appear more than once in over fifty percent of the transcripts. No rationale is offered to support this criterion, creating the impression that it has been arbitrarily generated. In addition, there is a danger that issues that have great significance to some, but not fifty per cent, of participants might receive less consideration in the analysis.

Findings

Creating categories of the complex findings of these 18 exploratory studies, that have been generated from different groups of participants using a range of methodologies, has been challenging. Notwithstanding the undoubted overlap in places, four themes have

been created: receiving and disclosing the diagnosis, accessing information and services, the effect on the family, and experiencing loss.

Receiving and disclosing the diagnosis

A common theme arising in virtually all the studies, the experience of diagnosis was often problematic. Carers of people with young onset dementia often found the journey to diagnosis for their family member convoluted, with misdiagnoses, complex service pathways and a lack of professional awareness that dementia can occur in younger people (Lockeridge & Simpson, 2012), leading Harris (2004) to conclude that being younger was a barrier to a timely diagnosis. Some participants with young onset dementia also commented on the length of time it took to get a diagnosis, the blunt manner in which the diagnosis was given (Beattie et al., 2004), and their shock at receiving it. For Clemerson et al.'s (2014) participants, the diagnosis was experienced as a profound and unanticipated disruption in their life course; they associated the condition with older age and considered themselves to be ageing prematurely. In some instances, participants became aware of their cognitive difficulties in a work environment and sought a diagnosis because of being unable to perform existing or new tasks (Johannessen & Möller, 2011), an occurrence likely to distinguish their experience from that of older people with dementia (Harris, 2004).

Some of the children of younger people with dementia in Allen et al.'s (2009) and Svanberg et al.'s (2010) studies, while noticing changes in the behaviour of their parents, had difficulty accepting the diagnosis, and while within families there was openness about the condition, many chose not to disclose the diagnosis to people outside the family due to stigma (Allen et al., 2009), fear of social isolation or a sense of shame (Hutchinson et al., 2014). In Hutchinson et al.'s (2014) study, a participant chose not to reveal her parent's diagnosis to her employers in case they thought she was also at risk of developing the condition and her career was adversely affected as a result.

Similarly, some of the participants with dementia struggled with issues of stigma or embarrassment when revealing their diagnosis to others (Johannessen & Möller, 2011)

and having to negotiate the misconceptions and assumptions that other people made (Beattie et al., 2004; Johannessen & Möller, 2011; Clemerson et al., 2014). Some people with dementia in Pilon-Young et al.'s (2012) study opted not to disclose their condition for fear of the adverse reaction of others.

Awareness of dementia beyond the family, when it did occur, did not necessarily lead to greater support; most of the children in Svanberg et al.'s study (2010) felt that their teachers were aware of their parents' diagnoses but only one participant reported being offered support from school, even though some felt that the experience of dementia had an impact on their education, a finding that also emerged in Forrest Keenan et al.'s (2007) study. In Barca et al.'s (2014) Norwegian study of adult children, there was a clear sense that their needs were neglected by statutory services, leading the authors to recommend the implementation of a family-oriented programme of support.

Accessing information and services

There was diversity in the expressed need for information; spousal carers seemed to be more likely to seek information than children of people with young onset dementia. For instance, some carers reported using the internet to gain information (Lockeridge & Simpson, 2012; Ducharme et al., 2013) and needing to be assertive to access services and information (Lockeridge & Simpson, 2012; Oyebode et al., 2013), while others felt that information about what to expect in the future should be provided at the time of diagnosis (Flynn & Mulcahy, 2013). In contrast, children of younger people with dementia seemed to be less likely to seek information; Svanberg et al. (2010) found that most of their participants did not want more information about their parents' conditions, and only some of the participants in Forrest Keenan et al.'s (2007) and Allen et al.'s (2009) studies wanted to know more about young onset dementia. Barca et al. (2014) found that amongst the adult children in their sample, there was a desire for greater information for the public and for themselves.

In addition, nearly all the studies highlighted the lack of appropriate service provision; the disjunction between the needs of the people with dementia and the available services

was a key issue for study participants (Bakker et al., 2010; Lockeridge & Simpson, 2012; Oyeboode et al., 2013; Flynn & Mulcahy, 2013; Barca et al., 2014). The most common issue reported with services was the inappropriateness of placing younger people in settings designed for older people (Clemerson et al., 2014).

In addition, Bakker et al. (2010) and Barca et al. (2014) noted that health services need to be responsive to the changing preferences of people with dementia and their carers as the condition progresses. Ducharme et al. (2013) argued that services should empower carers to feel able to access both formal services and informal help by expressing their needs to other family members.

The effect on family relationships

As well as a reluctance to access more information about the condition, children of parents with young onset dementia seemed to be more likely to adopt avoidant coping strategies. Many of the participants in these studies found a way to distance themselves from the parent with dementia, whether emotionally (Svanberg et al., 2010) or literally, by leaving the parental home (Allen et al., 2009; Millenaar et al., 2013; Hutchinson et al., 2014). Barca et al. (2014) noted a sense of relief was experienced when adult children became old enough to move out of their parents' homes, although they continued to experience a constant worry about their parent with dementia.

Drinking and smoking were also perceived as coping strategies by participants in Allen et al.'s (2009) study. Other coping strategies noted by Forrest Keenan et al. (2007) were assimilation, normalisation, problem-solving, and having a positive attitude, a finding also noted by Svanberg et al. (2010).

Other findings relating to the effect on the family are pertinent to the children rather than the spouses of younger people with dementia. For instance, parentification was a common theme in all of the studies of young people, with young people taking on a parental role by providing instrumental care and support. In Svanberg et al.'s (2010) study, the acceptance of this role had led to a rapid increase in maturity, and the unaffected parent was viewed more as an equal than a parent, a finding that was

mirrored in Millenaar et al.'s (2013) study. A related theme was the expression of fear of burdening the unaffected parent with their own worries and concerns, leading the young person to be, in Forrest Keenan et al.'s (2007) terms, the '*linchpin*' (p.123) of the family. Participants in Barca et al.'s (2014) study noted the support they received from siblings and partners, although the impact of the condition could be experienced differently by siblings in terms of their roles and responsibilities, depending on age, gender, and co-habitation.

Heritability was another salient issue for young people, particularly in Forrest Keenan et al.'s (2007) study of young people in families affected by Huntington's disease.

Huntington's disease is a rare form of dementia with autosomal dominant inheritance and the carrier status of individuals can be established through predictive testing. While other dementias may be inherited, the genetic link is less well understood, and it is therefore unsurprising that this study elicited themes from the young people regarding concerns about taking the predictive test and the possibility of developing the condition in the future.

The participants in Johannessen and Möller's (2011) study did not discuss in depth the effect of dementia on the family, and while openness about the condition was common, the experience of dementia as a health condition was not discussed between family members. However, role change emerged as a theme in Harris's (2004) and Barca et al.'s (2014) study as relationships were renegotiated within the family and family members had to adapt to new roles.

The changes in relationship between the younger person with dementia and their primary carer (Ducharme et al., 2013; Oyeboode et al., 2013), together with having to combine the caring role with also having dependent children and elderly parents was a particular problem for some of the carers in Ducharme et al.'s (2013) and Flynn and Mulcahy's (2013) studies. In addition, Harris and Keady (2009) and Oyeboode et al. (2013) found that sexual relationships between spouses became less enjoyable because of perceived incongruity between the caring and sexual roles. Denial of the condition by others was a finding in two of the studies (Harris, 2004; Pison-Young et al., 2012) which could potentially have very isolating effects for the younger person with dementia.

Indeed, Allen et al. (2009) found that isolation and resentment could also be caused by relatives in the wider family structure who distanced themselves from the person with dementia.

Harris and Keady (2009) also discuss other identity transitions as the carers' sense of themselves as workers, social beings and family members also transform as a result of the experience of young onset dementia. Oyebode et al. (2013) found that some carers discovered a sense of their own strength at coping with adversity, while Bakker et al. (2010) in their case study noted the tension between the spouse's dedication to caring for her husband and managing their own life and future.

Roach et al.'s (2013) study was the only one to conduct research with several family members. Congruent with the narrative design utilised, storylines of family experiences of young onset dementia were identified. These were agreeing, colluding, conflicting, fabricating and protecting. In the agreeing storyline, there was a strong cohesion between family members and a shared storyline of the experience of young onset dementia. Colluding storylines occurred when a section of the family was excluded from the core family narrative. Conflicting storylines were characterised by disagreements and strained relationships within the family. Fabricating storylines were used to portray the family dynamic in a positive way to the researcher and to obscure difficulties in relationships. These difficulties were revealed to the researcher as the family's familiarity with her increased. Finally the protecting storyline was used to protect children and grandchildren from the effects of the symptoms of the dementia.

Family conflict was identified in three other studies by young people with a parent with young onset dementia. A greater amount of friction in the family as a result of the young person having to take on caring responsibilities was reported by Millenaar et al. (2013) and Barca et al. (2014), and the lack of acknowledgement of this contribution by the parent without dementia combined with the stresses of caring caused conflict for some of the participants in Svanberg et al.'s (2010) study.

Oyebode et al. (2013) found that developing a sense of acceptance of challenging situations, distraction and humour all helped them to cope. Telling white lies to the person with dementia was also utilised as a coping strategy, as was concealing the

diagnosis from them and from other family members (Ducharme et al., 2013). Some carers chose to deny the presence of dementia themselves (Lockeridge & Simpson, 2012).

Experiencing loss

Several forms of loss were identified by participants in the studies: loss of independence, occupation, financial security, loss of self, and loss of an anticipated future.

In two of the studies with younger people with dementia issues were raised regarding the lack of occupation following an unplanned early retirement (Harris, 2004) and strategies adopted to cope with memory loss (Pipon-Young et al., 2012). Financial dependency on other family members (Harris, 2004), reduced income and losing the ability to drive seemed particularly difficult for some participants with dementia to accept (Johannessen & Möller, 2011). The loss of financial stability and difficulty accessing benefits was an issue raised by carers, particularly in Flynn and Mulcahy's (2013) study. Loss of a pre-illness identity, agency and self-worth was noted by Clemerson et al., (2014), as people with dementia struggled to manage threats to self imposed by dementia.

Restricted opportunities were also reported by children of younger people with dementia. Young people may become carers at a time in their lives when they are seeking to develop a greater level of independence. In this group of studies, such changing roles in the family resulted in restrictions in opportunities for some of the young people (Millenaar et al., 2013; Hutchinson et al., 2014) with some reporting giving up scholarships. This theme was less apparent in Svanberg et al.'s (2010) study, probably because of the younger age of the participants.

Loss of stability in the home was expressed in increased family conflict (Svanberg et al., 2010; Millenaar et al., 2013). The participants in Allen et al.'s (2009) study also described the loss of the 'real' father, while the younger participant in Svanberg et al.'s (2010) study describe trying to retain the memories of when their parent was well. Others noted a loss of their own mental health, with some young people experiencing psychosis and depression (Hutchinson et al., 2014). In Svanberg et al.'s study (2010), quantitative

measures indicated that two of the twelve participants had a major depressive episode, and seven were experiencing high levels of burden.

Keeping active and involved was a key theme in the interviews in Pison-Young et al.'s (2012) study, with people actively engaging in strategies that they believed might delay the progression of the disease, such as crosswords and other puzzles. Engaging socially with other people with dementia enabled some participants to feel a sense of a shared identity. This is important for a condition which can lead, as Harris (2004) found with her participants, to '*extreme social isolation*' (p. 29) and marginalisation.

A further key finding of this group of studies is the loss of independence and agency (Harris, 2004; Pison-Young et al., 2012; Clemerson et al., 2014) and the sense of having to rely on others at an unexpected stage in their life course, a concept Harris refers to as '*off-time dependency*' (p.29). Losing enduring, multiple roles, such as employee, home-maker, and the ability to drive were seen as particularly difficult to accept.

In addition to changes in the dyadic relationship (Oyebode et al., 2013; Flynn & Mulcahy, 2013), the loss of an anticipated future was also very challenging for carers to come to terms with (Lockeridge & Simpson, 2012; Oyebode et al., 2013; Ducharme et al., 2013). Some carers found the diminishing abilities of the person with dementia difficult to adjust to (Lockeridge & Simpson, 2012), and unusual behaviours occurring as a result of frontal variant fronto-temporal dementia in Oyebode et al.'s (2013) study caused embarrassment to carers in social situations.

The prospect of social embarrassment led to social isolation and the loss of friendships in Ducharme et al.'s (2013) study, although Flynn and Mulcahy (2013) found that their participants placed great value on the support of remaining friendships.

The link between findings and theory

These studies have created detailed understandings of the experiences of living with young onset dementia. Studies have generated lists of salient themes, yet, disappointingly, there has been only limited attempt to demonstrate theoretical linkage

between the themes generated in these qualitative studies, which would be expected particularly from those with a grounded theory methodology. In addition, some themes, especially those in Papon-Young et al.'s (2012) study, have received only the briefest of descriptions, making it difficult to ascertain how robust the themes are.

Other studies in the body of literature are more theoretically developed. Allen et al. (2009) for instance, in their study of the psychological and emotional impact on young people of caring for younger people with dementia, developed a diagrammatic model identifying the relationships between the concepts that emerged from the data, rather than providing a list of the emergent themes. In addition, they considered their findings in the light of other theoretical constructions, for example attachment theory, Pearlin et al.'s (1990) stress process model and Doka's (1989) concept of disenfranchised grief. Similarly, Hutchinson et al. (2014) use Oliver's (1983) social model of disability as a theoretical framework to explore the impact of young onset dementia on the young family members, concluding that young people with a parent with young onset dementia face exclusion and discrimination. This study is somewhat unique in the young onset dementia literature in that it draws attention to social structural factors rather than just focussing on the insider perspective.

Roach et al. (2013) in their study of the family experience of young onset dementia, make limited reference to Rolland's (1984) Family-System-Illness model, yet miss the opportunity to draw on the rich seam of family sociological theory to inform and enrich their interpretations of the data produced by the research process. Lockeridge and Simpson use Lazarus and Folkman's (1984, cited in Lockeridge & Simpson, 2012) model of emotion-focussed and problem-focussed coping strategies to inform their study, while Flynn and Mulcahy's (2013) study of seven caregivers living in Ireland utilised a conceptual framework of caregiver burden (Chou, 2000, cited in Flynn & Mulcahy, 2013). However, while they relate their findings to those of other studies on young onset dementia, they do not reflect on Chou's model with the data they collected, thus missing an opportunity to extend, amend or validate Chou's conceptualisation of caregiving burden. Clemerson et al. (2014) refer briefly to Erikson's (1963, cited in Clemerson et al., 2014) theories of psychological tasks that must be completed at certain ages in the life course, but again relate their data to the theory in a limited way. Within the parameters

of their study there is potential for them to use Bury's (1982) framework of biographical disruption to gain greater insights into their participants' experiences, but they do not make any reference to Bury's work.

The general lack of theoretical development constitutes a missed opportunity to extend knowledge. For example, while one of the studies attempted to explore the effect of young onset dementia on selfhood, social psychological or philosophical theories of the self could be considered in the light of the data collected and analysed. Conceptual frameworks from the sociology of chronic illness such as Charmaz's work (1983, 1991) on chronic illness and selfhood, Bury's (1982,1991) insights into biographical disruption, Goffman's (1963) notions of stigma and Giddens' (1991) concept of fateful moments could potentially be brought into conversation with the findings of this collection of research studies. In addition, within the young onset dementia body of literature, temporality is rarely considered explicitly; yet in a progressive terminal condition where people become more acutely conscious of finitude there may be much to be learnt from the ways in which people and their families construct meanings of remaining time. Using a qualitative longitudinal methodology, combined with sociological concepts, therefore, has the potential to offer unique insights into the experience of living with young onset dementia.

Furthermore, a limitation of both the sociology of chronic illness literature and the young onset dementia literature is the lack of focus on developing intergenerational understandings, and an exploration of how illness can affect entwined biographies. Hence there is less opportunity to use ways of theorising about family relationships, such as Finch's (2007) family displays and Morgan's (2011) family practices, to develop knowledge about the kinds of processes that can occur within families when one person develops young onset dementia.

Even within the broader field of dementia, intergenerational understandings of the experience of the condition are remarkably few in number (Purves, 2010; La Fontaine & Oyeboode, 2014). Purves (2010), for example, explored positioning within a family and found that family members individually and collectively struggled to reconcile the person with Alzheimer's disease with the person with whom they had a long, shared history,

while Smith and Kobayashi (2002), in their study of an intergenerational Japanese-Canadian family found that the responses of family members varied according to the ways they interpreted the symptomatology of the person with dementia in light of their identification with the norms and values of the Japanese culture. The importance of the historical context of the family was also acknowledged by Ward-Griffin, Oudshoorn, Clark and Bol (2007) in their study of mother-adult daughter relationships and by Forbat (2003) in her study of a single mother-daughter dyad.

Summary

These studies have created detailed understandings of the experiences of living with young onset dementia. However, the extent to which they illuminate the effect of the condition on relationships is limited. Therefore, in order to enrich our current comprehension of young onset dementia, and add new knowledge to current understandings, it is necessary to look more broadly at the social networks surrounding people with young onset dementia, and to engage participants longitudinally to capture these dynamic processes over time.

The only study that has attempted to take such a broad view is Roach et al.'s study (2013). While this research offers a fascinating and original insight into the storylines created by families in response to young onset dementia, it does have limitations. For example, there is little sense of the processes families might undergo as they move from one storyline to another. The longitudinal nature of the study is not conspicuous in the published work, giving a static feel to the analysis, so the potential of the research to capture dynamic change over time is not fully realised.

Significantly, the lack of intergenerational family constructions means that the extent to which creating understandings of relational change within larger families is constrained. In particular, there is a dearth of knowledge of the experiences of parents, grandchildren and friends of people with young onset dementia.

The review of this body of literature has informed the focus of this doctoral research. The importance of gaining insiders' views of what it is like to live with young onset dementia

has been inspired by both the sociology of chronic illness literature and the young onset dementia literature. Furthermore, the existing gaps in both fields of knowledge, i.e. the lack of intergenerational family perspectives captured over time, represent neglected aspects of knowledge in the bodies of literature which this doctoral research aims to address.

A key critique of the young onset dementia body of literature identified in this review is the lack of theoretical frameworks informing the research, and therefore an opportunity exists to contribute to the knowledge base by constructing a study with cogent theoretical foundations. The next chapter outlines the theoretical arguments that underpin this study, demonstrating the connections between these approaches and the methodology chosen to generate unique knowledge about the intergenerational context in which young onset dementia is lived.

Chapter Four : Theoretical Frameworks

Introduction

This chapter will outline the most appropriate ontological and epistemological position for a study on intergenerational experiences of young onset dementia. I argue that, as this study seeks to gain sociological insights into insider perspectives of the complex experience of young onset dementia, a symbolic interactionist approach, which focuses on intersubjective creation and refinement of meaning, is the most appropriate orientation for this study. However, I concur with Gabb (2008), who has argued that a singular theoretical framework is insufficient to generate understandings from the complexities of a qualitative longitudinal data set, and I have therefore adopted a pluralist approach to frame this thesis, interweaving symbolic interactionism with family sociology, the sociology of personal life and the concept of belonging. These congruent approaches share a temporal, intersubjective approach to the understanding of human social life and offer a coherent orientation for developing unique insights into how young onset dementia is experienced in a broader relational context.

Four main facets of the theoretical approaches and their relevance to creating sociological understandings of the experience of young onset dementia will be explored in this chapter: meaning-making processes, relationality, temporality and selfhood. These dimensions are implicated within each other and interweave in complex ways; meanings are constructed with others over time and mediated through our sense of self as we develop understandings of the ways in which we belong to our social worlds (May, 2013, 2016b). Therefore, these facets are not presented as discrete, bounded concepts but rather as varying angles from which the holistic lived experience of young onset dementia can be explored.

The chapter will conclude with a discussion of how the theoretical frameworks have informed the choice of the methodological approach adopted in the study.

Meaning-making processes

From a biomedical perspective dementia would be viewed as a progressive neuropathology which manifests through increasing impairment of cognitive processes and ensuing difficulties with the activities of daily life (Bond, 2001). However, this standpoint gives no insight into how people generate and refine meanings around the condition and how it shapes their understanding of their place in society, their biography and their relationships with others. Exploratory sociological research into insider perspectives of young onset dementia, therefore, necessitates a focus on how meanings of the condition are intersubjectively created and refined over time. Micro-sociology, with its emphasis on human agency, concrete interaction and meaning-making processes is therefore the most appropriate orientation for this study.

Although there are several different approaches within micro-sociology, for example phenomenology and ethnomethodology (Calhoun, Gerteis, Moody, Pfaff & Virk, 2012), perhaps the most prominent form, and the most appropriate for this study, is symbolic interactionism. Established by Herbert Blumer, and founded on the work of George Herbert Mead, symbolic interactionism has its roots in American pragmatist philosophy and social behaviourism. From an ontological perspective, symbolic interactionism contends that meanings are actively created as social actors act towards each other, their environment, and themselves. In contrast to a structural functionalist perspective which views human agents as responding to the social order of a reified society, a symbolic interactionist orientation emphasises the lived experience of interacting social agents and is a dynamic and processual approach to the understanding of human social life (Hewitt, 1976).

The central claims of symbolic interactionism are that people act on the basis of the meanings they have; that these meanings are generated by people in social interaction through the use of verbal and non-verbal symbols, that social actions are shaped by people's interpretation of meanings, and that social life is fluid and continually being renegotiated by the interaction of social actors. The intellectual influences of pragmatism and social behaviourism are perceptible in these central claims; that people act towards things on the basis of 'what works', and that reality does not impose itself on people,

rather that people actively create realities through their engagement with the world (Charon, 1998). Symbolic interactionism, therefore, places a strong emphasis on the agency and interaction of social actors; the disinclination to reify social structures is matched by a reluctance to focus on the internal drives of the individual human psyche. Thus symbolic interactionism takes as its primary interest the interaction between people which shapes the meanings they ascribe to social life.

Symbolic interactionism is, therefore, an apposite overarching perspective for this study. Identified by Conrad and Barker (2010) as one of the most influential intellectual traditions guiding research on the subjective experience of chronic illness, symbolic interactionism offers a means of exploring the ways young onset dementia is endowed with meanings in daily life. These meanings do not inhere within dementia, but are developed and continually redefined through social interaction; moreover, they shape the sense of self and identity as people reflect upon what other people say, or do not say, and how they act. Individuals are, therefore, engaged in a continuing process of generating meanings about illness based upon their experience of social interaction (Charmaz, 2002; Kralik, Koch & Eastwood, 2003). This perspective, therefore, encourages direct exploration of the empirical world of people experiencing young onset dementia in order to gain an understanding of meanings that are intersubjectively created and understood within their worlds (Blumer, 1969).

The utilisation of symbolic interactionism as a perspective from which to produce meaningful insights into the experience of ongoing illness has found expression in Bury's (1982) concept of '*biographical disruption*' (p. 167) and Charmaz's conceptualisation of illness as interruption, intrusion and immersion. Biographical disruption describes how people can view chronic illness as a disruptive force in three domains: assumptions and behaviours, biography and sense of self, and the allocation of material resources. Created from his research into younger people with rheumatoid arthritis, there are parallels with my study population. In addition to the young age of onset, medical knowledge and treatment of both conditions is limited, and in the absence of external knowledge and predictability, people with young onset dementia and their family members and friends may create their own explanations of why the illness occurred, what factors affect its

impact on their biographies and what the future may hold. Biographical disruption is, therefore, a pertinent concept to inform a sociological study of young onset dementia.

Charmaz's (1991) conceptualisation of chronic illness as interruption, intrusion or immersion describes ways in which people make sense of chronic illness. In the first of these, illness as interruption, ill people can reframe the chronic condition as an acute and temporary problem that they, at some future point, will recover from. The second concept, of illness as intrusion, describes a situation where the chronic condition cannot be understood as a series of acute incidents, and, in contrast to illness as interruption, people are more likely to create strategies to manage their symptoms. Attempts to restrict the effects of the illness to the background rather than the foreground of their lives typifies the construction of the illness as intrusion. The final construct is illness as immersion. When the effects of an illness become inescapable, the lives of individuals are founded upon their physical condition, and time and self become reshaped.

As long as people with young onset dementia remain aware of the progressive nature of their condition it is unlikely that they would understand their dementia as an interruption; however, the extent to which they generate meanings of the condition as an intrusion, where dementia is constructed as an unwelcome backdrop to their lives or as immersion, where they invest time and self in dementia-centric activities, offers insights into their meaning-making processes. Furthermore, the use of a longitudinal methodology in this study allows for the emergence of understandings as to how these meanings may transition over time.

According to a symbolic interactionist perspective, the ways in which people create and refine meanings of young onset dementia is not in isolation, but through interaction with others, and therefore relationships are a central focus of this study.

Relationality

This study aims to generate understandings of how a serious progressive condition is experienced in a broader relational context. It is necessary, therefore, to outline the

theoretical approaches to understanding family and other personal relationships which inform the research.

Family relationships

Sociological understandings of family have undergone extensive change since the 1950s when Talcott Parsons theorised the nuclear family in terms of the functions it fulfilled in industrial societies (Cheal, 1991; White & Klein, 2008). Highly influential at the time, Parsons' theories have been extensively criticised, not least for their rigid, heteronormative portrayal of family and their patriarchal depiction of the gender division of responsibility within the home. There is little doubt that a Parsonian model of the nuclear family would fail to represent the increasing diversity of families in modern life; demographic changes have occurred which mean that less than a quarter of people in the UK now live in a nuclear family household (Finch, 2007). Moreover, continuing to use the term 'family' risks disadvantaging those living alone, parenting alone, being part of a same-sex relationship and being a couple without children.

In recent years there have been key shifts in sociological discussions which have moved the primary relational focus away from the term 'family' and towards intimacy (Jamieson, 1998) kinship (Mason, 2008) or the sociology of personal life (Smart, 2007), which encompasses a broader range of relationships. Whether 'family' should persist in contemporary sociology at all has been the source of much discussion and debate, particularly in the sense of whether the concept will be supplanted by the sociology of personal life (Edwards & Gillies, 2012), or whether these modes of conceptualising human relationships are complementary and can co-exist (May, 2012). The utility of the notion of family is, therefore, contested, and yet the term, while lacking analytical clarity, persists, suggesting it retains meaning and resonance.

For sociologists who continue to utilise the concept of family, there has been a clear move away from the static concept of 'being' family towards the dynamic concept of 'doing' family, notably in the guises of '*family displays*' (Finch, 2007) and '*family practices*' (Morgan, 1996, 2011). Within these conceptualisations, the locus of analysis is

repositioned away from 'the family' as a stable unit and towards sets of family activities defined as such by those participating in them. These conceptualisations are underpinned by a fluid notion of family, providing a means of theorising about family which recognises the continually evolving nature of family relationships and is able to accommodate the greater diversity of family relationships in modern social life. Family is, therefore, viewed less as a group with which one has genetic or affinal links and more as relationships that people attach a meaning of family to. For family practices or displays to be meaningful, they have to be communicated in ways that other people will understand them as family-related actions. As Finch notes:

'display is the process by which individuals, and groups of individuals, convey to each other and to relevant audiences that certain of their actions do constitute "doing family things" and thereby confirm that these relationships are "family relationships"'
(2007, p. 67).

The way family is expressed through the interactions of social actors creates, according to Finch (2007), a continually evolving framework in which those actors understand family, interpersonal relationships and their own identity. Likewise, Morgan (2011) emphasises notions of agency and change underpinning family relationships. He also acknowledges that family practices do not just appear; rather practices are influenced by processes of structuration such as cultural values and legal and economic positions. However, he does not view these as fixed structures, but evolving processes. This shift away from static envisionings of the family as an institution can also be located in Finch (1989) and Finch and Mason's (1993) work on family obligations and commitments, in which the sense of kinship responsibility is not perceived as a natural outcome of a cultural notion of duty, but instead is a product of intersubjective negotiation over time (Smart & Neale, 1999). For example, Finch and Mason (1993) describe the ways in which people within families construct '*moral reputations*' (p. 149), and interpret each other's reputations over time based on their behaviour in previous scenarios.

These ways of theorising about family have a strong synergy with symbolic interactionism, centring as they do on people's actions and how those actions are socially interpreted and understood, and therefore the use of an overarching symbolic interactionist perspective, combined with a longitudinal methodology that explores

change over time, is the ideal theoretical framework for this study on the intersubjective experience of young onset dementia. Utilising these theoretical approaches to family will enable a nuanced, dynamic view of the significance of family practices in the context of dementia rather than an oversimplified representation of how 'the family' responds to the condition.

Since the research also aims to gain an understanding of how friendships might be affected in the context of young onset dementia, this study can also draw on the sociology of personal life which encourages a focus on a broader relational context (Smart, 2007). Returning to May's (2012) assertion that family sociology and the sociology of personal life are not mutually exclusive, but can co-exist; these various theoretical strands combine to frame this doctoral study so that non-kin relational transitions in the context of young onset dementia can be explored.

The appeal of Smart's (2007) theorisation of personal life is in its breadth. Using Smart's framework, sociological researchers can seek to generate understandings about the personal lives of participants in their social contexts without the conceptual boundaries of kin and non-kin. In addition, the sociology of personal life can encompass various aspects of personal and social life including sexuality, embodiment, intimacy and emotions. While initially Smart's framework may appear to be individualistic in nature, she draws attention to the embeddedness of practices that characterise relationships as threads that are meshed or woven together, not to form static institutions, but to form habit, traditions and memories that can be renegotiated or reconfigured (Gilding, 2010). Smart (2007) argues that families play a particularly significant role in the construction and revisiting of shared memories over time and across the generations, and that this process is crucial to the ongoing reconstitution of those relationships. What happens when a family member with young onset dementia forgets significant shared memories, and the ways in which that might impact on family relationships, will be explored in this study.

Friendships

This study seeks to explore the effect of dementia on enmeshed intergenerational relationships. Restricting the study to a sole focus on kin relationships, in a similar way to Roach et al. (2013), risks assuming that kin relationships have greater significance in people's experience of young onset dementia than other forms of relationship. The significance of friendships in the context of young onset dementia is, therefore, an important area to explore, and one which has hitherto received very little attention (Harris, 2013).

Spencer and Pahl (2006) highlight the importance of friendship in people's lives and their conceptualisation can provide a theoretical framework to guide understandings of how young onset dementia affects such relationships. They describe four key concepts in friendship: '*friendship repertoire*'(p. 77) - the range and characteristics of friendship; '*friendship career*'(p. 72) - how the friendship evolves over time; '*nature of commitment* ' (p. 82), which refers to aspects such as loyalty and trustworthiness; and '*suffusion*' (p. 54), the extent to which kin and non-kin boundaries become blurred (Spencer & Pahl, 2006). This blurring of boundaries, while often assumed to be a positive experience (Heaphy & Davies, 2012) can lead to tensions within relationships due to the lack of clarity about expectations.

Spencer and Pahl's conceptual framework has been successfully used by Harris (2013), who explored the quality of friendships of people with dementia. She notes that, rather than assuming that a diagnosis of dementia can cause friends to withdraw from the relationship, in some instances it can be the trigger that strengthens friendship ties. It is important within this study, therefore, to avoid preconceptions that friends distance themselves from participants living with young onset dementia, and to explore instead continuities and transitions in friendship relationships over time.

Belonging

May's (2013, 2016a, 2016b) notion of 'belonging' also provides a useful lens to gain insights into relational experiences in the context of dementia. Belonging, to May, is a

crucial aspect of selfhood as people's understanding of themselves is contingent on where and with whom they feel they belong and takes place in intersecting domains such as cultural, sensory and relational levels. Belonging to family or kin groups, it has been argued, is different to belonging to other social groups (Skaff & Pearlin, 1992; Finch & Mason, 1993; May, 2013), in that there is a sense of permanence about family relationships, even if they are inactive for long periods of time. May argues that the notion of belonging, in comparison to the more frequently used concept of identity, has a more relational than individual connotation, drawing attention to the connectedness of people rather than envisioning people as autonomous individuals. Moreover, assigning people to identity categories may do them a disservice since explanations of their experiences are subsequently situated in relation to the category. May contends that if the category in question is marginalised due to stigma, such as dementia, it is particularly important to understand the perspectives of those socially assigned to that category. Younger people with dementia can experience processes of social exclusion within the official sphere because of their condition; the most obvious of these being classified as unable to work and to drive. As their lives as independent persons are constrained, and their sense of exclusion increases as their notions of 'normal' life are challenged, it may be that they act to create other forms of belonging.

Belonging is a multifaceted concept that describes the ways in which people develop and experience a sense of attachment, and while often conceptualised as belonging to a place, to people or to a generation (May & Muir, 2015), it is conceivable that people can 'belong' to an illness experience. In the context of young onset dementia, concerns about forgetting significant people and a diminishing sense of capability may impact on the extent to which people consider themselves as belonging to their social networks, communities and to society as a whole. However, engaging with social groups for young people with dementia may engender a new sense of belonging which can be explored during this study.

May (2016b) has emphasised the temporal dimensions of belonging, arguing that exploring time and belonging gives us insights into how people construct and continually redefine their sense of self. Morgan (2011) has also drawn attention to the importance of time in family relationships, noting that:

*'not only do family members use and negotiate about time on a regular basis but they are also located within time in certain distinct ways. Indeed in a certain sense it could be argued that family practices are **about** time... pasts and futures are rehearsed and recollected in the co-presence of these others, of different generations'* (p. 79, original emphasis)

Developing understandings of how people with young onset dementia and their families and friends subjectively experience time has been largely neglected in young onset dementia research and is an important dimension of this study.

Temporality

In the context of young onset dementia, time is clearly a pertinent topic of study in at least two respects. Firstly, a diagnosis of a progressive, terminal disease such as young onset dementia is likely to be perceived as a *'fateful moment'* (Giddens, 1991, p. 202) in which individuals are suddenly confronted with a shortened life and a drastically altered future. How people living with young onset dementia structure and experience time is an important avenue of enquiry. Secondly, developing a condition more commonly associated with later life (Chaston, 2011) in mid-life may challenge the normative expectations that people may have about health and illness in relation to their life course, previously described as the *'social clock'* of illness by Bury and Holme (1991, p. 94). Thus a focus on the temporal enables a way of gaining insights into how individuals and their families and friends living in the context of young onset dementia construct meanings of young onset dementia and how they perceive their shared past, present and future.

Despite the pertinence of temporality in the lived experience of young onset dementia, time has received virtually no attention in existing research studies. This oversight is not unique to this topic of enquiry; according to Adam (1990) the taken-for-granted nature of time renders it almost invisible in social science research. However, there have been recent calls for a more explicit focus on time: Thomson (2014a), for instance has observed both a theoretical and an empirical *'turn to time within social research'* (p. 148). As time is at the heart of any socially negotiated activity, there is a strong synergy between the construction of time and interactionist perspectives. Time, in Mead's view,

is not linear since the past is selectively reconstituted in the present, and thus is as hypothetical as the future (Maines, Sugrue & Katovich, 1983; Maines, 2001; Daly, 2002). As Maines et al. (1983) note, the past has both happened and is happening as it is symbolically reconstructed in the present. In the context of a condition that affects memory, such as young onset dementia, there may be a lack of congruity between individuals' reconstructions of the past which may unsettle relational processes (Smart, 2007; Morgan, 2011).

Interactionists, as Daly (2002) asserts, perceive time to be a phenomenon that is subjectively experienced within the self, and intersubjectively experienced in social interaction. As Maines et al. (1983) suggest:

'Mead's keen understanding of the dialectics of temporality focused on the use value of pasts and futures for the present. This process is necessary for human association as people collectively construct, maintain and transform their relationships on the basis of their utilization of time' (p.168)

Exploring changes and continuities in the experience of young onset dementia will be elucidated by a focus on the symbolic reconstructions of the past in the present, and by developing an understanding of the parameters of an anticipated future shaped in the emergent present.

Although few scholars have paid attention to the subjective experience of time in the context of illness (Årestedt et al., 2014), Charmaz (1991) has notably explored this area. Taking a symbolic interactionist approach, she argues that meaning-making processes are:

'imbedded in experiences of time...being ill gives rise to ways – often new ways – of experiencing time... meanings of illness and self take root in subjectively experienced durations of time' (p.4)

The participants in Charmaz's study were experiencing a range of chronic conditions, such as multiple sclerosis and emphysema, and some were having to cope with the onset of conditions at a younger age than might be anticipated. However none of them were diagnosed with dementia. Since, as John Locke proposed (Unger, 1990), memory plays a crucial role in one's identity and in one's biographical narrative (Giddens, 1991)

how young onset dementia affects people's sense of a continuing self and disrupts their ontological security, ie. their '*sense of the very reality of things and of other persons*' (p. 36), may be illuminated through considering their temporal landscape. A symbolic interactionist perspective has the potential to provide a nuanced and intricate understanding of how intergenerational relationships in the context of young onset dementia are affected over time and how the diagnosis of young onset dementia may affect the subjective experience of time.

Charmaz (1991) described the interrelatedness of time, selfhood and chronic illness in the following way:

'Time plays a central, albeit hidden, role in shaping self concept...an irretrievable past, an unsettling present, and an irrevocably changed future alter an individual's view of self. These altered views reflect shifts in the relatively stable foundation of the self-concept; the structure of it changes'
(p. 229)

The experience of changes in selfhood over time may be compounded by the effects of a health condition such as dementia where cognitive decline and memory loss are common experiences. In dementia, therefore, the past may be 'irretrievable' not because of a lack of ability to inhabit the previously healthy body but because memory loss renders aspects of it unreachable. Although Charmaz (1995) has argued that loss of self can occur in the context of illness where people are forced to reconsider past, present and future identities, in the context of dementia, past identities may be inaccessible because of a fragmented or absent memory. Therefore this study will utilise the concept of self to explore how young onset dementia impacts on lives.

Selfhood

Charmaz's (1991) work highlighted the effect of chronic illness on people's subjective experience of time and their sense of self. In the context of young onset dementia, notions of self and identity transitions over time are perhaps yet more pertinent as the condition affects cognitive processes including memory, the existence of which has been viewed as essential for the experience of a coherent self (May, 2016a, 2016b). In

exploring the insider perspective of young onset dementia then, it is important to consider how self and identity evolves over time as a consequence of the condition. Notions of the self and how the self, as a process, emerges through time, are pivotal in symbolic interactionism (Burkitt, 2008; Ritzer & Stepnisky, 2014) and therefore this approach is an ideal lens through which to view self and identity in the context of young onset dementia.

Mead (1934) has offered a distinctive view of the self that informs the symbolic interactionist perspective. In his view, the self is both object and process that arises through social interaction. Since the development of the self is dependent upon this interaction, it is logical to suggest that the self is not static but is in a constant state of being defined and redefined. The self in Mead's view is neither akin to Freud's notion of ego nor to an immaterial soul, rather, it is an object that we act towards in the same way we act towards other people. Therefore, we are able to consider ourselves in relation to situations; to judge ourselves, to consider others' perceptions and understandings of us and to devise ways of symbolically communicating with them. Our sense of who we are directs our action in the social world and enables us to make choices dependent upon our interpretation of situations. How people with young onset dementia interact in their various social spheres has consequences, then, for the way they view themselves and others and shapes their sense of belonging (May, 2016b) to the social world.

Goffman's (1959) dramaturgical analysis of how the self is presented owes much to Mead's construction of the self (Ritzer & Stepnisky, 2014). Goffman suggests that in social interactions, participants attempt to manage the impressions that the others form of them, and that audiences tend to accept the self that performers project. However, unexpected behaviour, such as that which may be displayed by a younger person with dementia, may disrupt a social performance, giving actors the sense of a '*false note*' (p.235), causing awkwardness and embarrassment. Goffman's concept of '*impression management*' (p. 203) therefore has utility for this study, along with his related definition of stigma, which will be returned to later.

Selfhood and dementia

Self, then, is a core concept within symbolic interactionism, and the question of what happens to the self in the context of dementia is one that has sparked considerable interest and debate. For example, the question of whether selfhood is contingent upon memory, or whether selfhood is an embodied rather than a purely cognitive phenomenon, has been raised (Burkitt, 1998; Kontos, 2004).

One of the earliest considerations of selfhood in dementia was provided by Cohen and Eisdorfer (1986) in *The Loss of Self*, who argued that the person with dementia inexorably lost their sense of self, gradually becoming subsumed by the disease (Perry & O'Connor, 2002). If one interprets the experience of dementia through the traditional concepts of personhood, for example, rationality, the ability to communicate, and intentionality, it could be suggested that the selfhood of a person with the later stages of dementia is indeed eroded. Yet this pessimistic view that people with dementia ultimately lose their selves has been challenged by the social constructionist model of self (Kitwood, 1997; Beard, 2004; Sabat, 2005). Within this model, the view of loss of personhood in dementia being entirely consistent with neurological deterioration is seen as inaccurate; rather the way people with dementia are undermined through processes such as mockery, infantilisation, stigma and disparagement by others affects their sense of self. These, and other elements of Kitwood's '*malignant social psychology*' (p. 46), depersonalise people with dementia, and, he argues, are deeply damaging to their self-perception.

A study that has used the social constructionist view of self is Sabat and Harré's (1992) research on the construction and deconstruction of self in Alzheimer's disease. The social constructionist model of self is composed of either two or three dimensions depending on whether the earlier or later version of the model is used. There is a personal identity self (Self 1), a self of beliefs and values (Self 2) and a multiple social self (Self 3) which becomes apparent in social interaction. All three forms of the self utilise language which makes the selves accessible to researchers using interview techniques. The presence of Self 1 can possibly be ascertained by the use of the first person indexical: I, me, my, myself, mine. Studies that have explored Self 2 have found that people with dementia were able to discuss past and present attributes. The studies that explored Self 3 were

based on case studies, and suggested that multiple social selves persist until the later stages of the illness.

The question of to what extent the self persists in dementia has received continuing attention in the literature. However, as Caddell and Clare (2010) noted, this field of enquiry is hampered by the lack of clear theoretical frameworks guiding the research. For example, even though Harris and Keady's (2009) paper on selfhood in young onset dementia is not included in their review, it is an example of a paper that has explored selfhood without articulating a definition of the concept. In addition, other scholars have drawn on a variety of conceptual models of the self which has resulted in a fragmented body of knowledge. For example, within the qualitative research domain, Caddell and Clare (2010) recognised four models of the self: social constructionism; interactionism, embodied selfhood and the self as narrative. Quantitative attempts to measure aspects of the self focus on components or abilities thought to be representative of a self, such as self-recognition of one's own image, rather than exploring the self as a holistic construct. Caddell and Clare (2010) suggest that their findings indicate that future research needs to be conducted within a clear theoretical framework, however, this somewhat overlooks the fact that even established theories are still evolving. For instance, Karner and Bobbitt-Zeher (2006) suggest that there is ambiguity even within Mead's conception of selfhood, and that *'as interactionists, we are left with more questions about what constitutes selfness than firm ideas of its elemental components'* (p.565).

Kontos (2004) integrated the work of Merleau-Ponty and Bourdieu to create a framework of embodiment, which demonstrated a coherent sense of selfhood is sustained at the pre-reflective level of experience. Grounding selfhood in corporeality, Kontos suggests, offers a challenge to the notion that human agency is contingent upon cognitive capability. However, Davis (2004) offers a different perspective of Merleau-Ponty's notions of embodiment, suggesting that in dementia, a deteriorating cognition erodes 'Being-in-the-world' through which the self fragments and cannot be restructured.

Giddens' (1991) view of the reflexive self in late modernity can also be considered in relation to dementia. According to Giddens, the erosion of tradition in the late modern age has increased the level of self-reflexivity, freeing people to construct biographical

narratives through the negotiation of lifestyle risks and choices (Heaphy, 2007). Giddens notes that central to self-reflexivity is the fundamental connection between language and memory that enables differentiation between different time horizons, and underpins individuals' biographies. Autobiography, Giddens argues, is key to self-identity. Therefore, if someone lacks a sense of biographical continuity, through the cognitive decline and memory loss associated with dementia, their sense of ontological security could be diminished, affecting the coherence of the self and increasing its permeability to tensions and changes in social environments.

Notions of the self in dementia, then, are complex, and considerable debate exists within social psychological, sociological and philosophical disciplines. Within this study, transitions in the self and identity in the context of young onset dementia will be explored to contribute to these ongoing discussions.

Stigma

Nettleton (2006) has described the significant influence of the concept of stigma on the field of chronic illness studies, and it is important to consider stigma in relation to young onset dementia. Stigma, defined as the process by which self-identity is adversely affected by the reactions of others, is a theme that has arisen in various empirical research studies on the experience of young onset dementia (e.g. Lockeridge & Simpson, 2013; Roach, Keady, Bee & Hope, 2013; Hutchinson, Roberts, Kurrie & Daly 2014) and has received considerable attention in the sociology of chronic illness. For example, in their study of people with asthma, Scambler and Hopkins (1988) described two types of stigma: enacted stigma, which describes the experience of discrimination resulting from social perception of inferiority of a person, and felt stigma, which describes the fear of experiencing enacted stigma. Joachim and Acorn (2000) draw attention to the relationship between visibility and stigma, arguing that people with an illness with fluctuating visibility may have a different experience to those people with either permanently invisible or permanently visible conditions. This could apply to people with young onset dementia, whose cognitive difficulties, particularly in the earlier stages of the condition, could be apparent in some social situations but not in others.

The social theorist most associated with stigma is undoubtedly Goffman (1963). Goffman purported that people become stigmatised when there is a disparity between their virtual social identity, what they ought to be, and their actual social identity, what they are. The nature of the interaction between those who are stigmatised and those who aren't depends, according to Goffman, on the type of the stigma. Goffman describes two types of stigma, discredited stigma, where the audience is aware of the differences, and discreditable stigma, where the differences are not known by the audience. In the latter instance, the actor has to manage the audience's impression of them so that the problem does not become known, whereas in the former, the person has to manage the tension created by the fact that the difference is known. Theoretically, people with young onset dementia would be more likely to experience discreditable stigma, since the condition would not be expected in a younger person. However, once the diagnosis is disclosed, or unusual behaviour creates awareness in the audience, discredited stigma could be experienced by the person with dementia and associative stigma, ie. stigma through association (Catthoor et al., 2015), could be experienced by their family members and friends. This study will utilise the concept to develop understandings of stigma in the relational context of young onset dementia.

Theoretical approaches and qualitative longitudinal methodology

It is important to explore the links between these theoretical perspectives and the epistemology that underpins the empirical study. I argue that symbolic interactionism, from an empirical perspective, is highly congruent with longitudinal methodologies, since it is a processual, temporal perspective that encourages the study of meaning-making processes over time. As Adam (2004) has observed, Mead (1932) is one of the few social theorists to explicitly discuss time, considering the contingencies of the past, future and the emergent present; the synergy between his approach and the temporal focus of QL research is, therefore, evident.

Since symbolic interactionism offers a way of understanding social worlds from the perspective of those who inhabit those worlds, exploratory qualitative research methods are the most appropriate. Indicating the unsuitability of methods from the quantitative

toolkit, Blumer (1969) notes that the form of data that is desirable within the symbolic interactionist framework is:

'rarely ... yielded by standard research procedures such as questionnaires, polls, scales, use of survey research items, or the setting of predesignated variables. Instead they are in the form of descriptive accounts from the actors of how they see the objects' (p.51)

Taking this stance to its logical conclusion, entering the social worlds of people with predefined notions of their experiences of young onset dementia would be a methodological error; it is incumbent on symbolic interactionists to determine problems, concepts and research techniques through examination of the social world. Thus it is necessary to consider which techniques are appropriate to gather information about that empirical world through direct engagement with it. Symbolic interactionism, therefore, encourages the imaginative use of data collection methods that are developed through engagement with the empirical world of those studied rather than being created *a priori*.

Jamieson, Simpson and Lewis (2011) have noted that there is something unique about conducting family or relationship research that distinguishes it from other forms of social inquiry. Exploring the experiences of families and friends living with young onset dementia from the perspectives of family practices, the sociology of personal life and belonging encourages a fluid, dynamic approach to how family and friendship is understood, experienced and expressed by the study participants rather than assuming that 'the family' is a given, static unit providing functional assistance to its members. Viewing relationality in the context of young onset dementia from these perspectives, I argue, enables a nuanced, complex view of the effect of a progressive condition on relationships over time, and a QL methodology offers a powerful means of creating this processual knowledge (McLeod & Thomson, 2009).

Adopting an overall symbolic interactionist perspective, then, with theoretical influences of family practices, belonging and the sociology of personal life enables a relational focus on the dynamic ways in which participants seek to socially create, define and renegotiate meanings when someone develops young onset dementia. As I have explicated here, the processual approach of symbolic interactionism is consistent with the temporal focus of qualitative longitudinal methodology adopted for this study. In addition, Blumer's (1969)

exhortations to researchers to enter the empirical worlds of the participants with an open mind, and to collect data in a way that is consistent with their worlds, supports the exploratory and creative nature of this study. There is, therefore, a cogent link between this theoretical framework and the chosen methodological approach.

Summary

In this chapter I have argued that a pluralist theoretical approach to the study of intergenerational experiences of young onset dementia is necessary given the potential breadth and depth of an exploratory study. Various congruent influences, such as notions of the self, the sociology of personal life, family practices and belonging, have been explicated under the mutually implicated themes of meaning-making processes, relationality, temporality and selfhood. Within these general intellectual domains, specific concepts such as stigma, ontological security, biographical disruption, and fateful moments have been identified in relation to their theoretical significance to this study. To borrow Mills' (1959) phrase, shuttling back and forth between these theoretical components and the empirical data will facilitate an original contribution to the knowledge of the effects of young onset dementia on intergenerational relationships.

I have argued that the theoretical arguments presented here frame the methodological approach adopted in this study. The next chapter outlines the methodology and design of the research in depth, elucidating how the study will contribute original knowledge to the existing body of literature. A comprehensive description of the research process will be provided, detailing the research questions, sampling strategy, ethical approach, data collection process and analytic strategies.

Chapter Five : Methodology

Introduction

Drawing together earlier discussions of theoretical frameworks and existing empirical studies, this chapter will provide a context, justification and detailed description of the design of this doctoral research. The ontological and epistemological underpinnings of the research will be discussed in relation to the methodology chosen to provide new knowledge in this important area of study.

The practical elements of conducting the empirical research are then described and explained. The design of the study, research questions, sampling strategy and recruitment are discussed, followed by an account of the analytic strategy and the presentation of findings.

Symbolic interactionism and qualitative longitudinal (QL) research

The philosophical underpinnings of this study lie in the interpretivist paradigm - specifically, symbolic interactionism. A highly influential tradition in sociological and social psychological thought (Ritzer & Stepnisky, 2014), and the sociology of chronic illness (Conrad, 1990), symbolic interactionism focuses neither on the personality of the individual nor structural societal influences on human behaviour, but on *'the nature of social interaction, the dynamic social activities taking place among persons'* (Charon, 1998, p. 27). As such, it is an ideal lens through which to explore and understand the relational response to young onset dementia.

With respect to the nomothetic-idiographic continuum (Finfgeld-Connett, 2010), symbolic interactionism has a particularistic stance; Blumer discusses the *'very different worlds'* (1969, p. 39) that are collectively formed by human beings. In order to understand these worlds, the researcher has to actively enter them (Schwandt, 1994) with a broad, open focus, which will gradually be refined and sharpened as the researcher comes to understand that world as it is formed, experienced, interpreted and redefined by the people within it. Researching how young onset dementia affects

families and friendships using the symbolic interactionist perspective will enable the creation of rich understandings about how the participants socially create, shape and renegotiate meanings of the condition over time.

Symbolic interactionism has a dynamic perspective on social life and interactions. Blumer notes that, for a researcher, it is '*necessary to view the given sphere of life... as a moving process in which participants are defining and interpreting each other's acts*' (1969, p.53). There are, therefore, strong synergies between the processual elements of symbolic interactionism and qualitative longitudinal (QL) research, the chosen methodology for the study.

Qualitative Longitudinal Research

For several decades QL methods have played a crucial role in developing nuanced and intricate understandings of social worlds. Perhaps most commonly associated with ethnographic traditions within social anthropology, QL methods have also been applied within other disciplines such as sociology, psychology and oral history (Holland & Edwards, 2014), and have recently received greater attention as a result of the Economic and Social Research Council (ESRC) Timescapes initiative (2007-2012), a series of studies exploring changes in identities and relationships across the life course.

The central feature of QL methodology is the focus on developing processual understandings; generating detailed insights into how people experience transitions and continuities over time in the context of broader social trends and shifts. Privileging the temporal and spatial, and the individual and social, QL methods aim to '*discern the logic of interior lives*' through developing awareness of the dynamic relationships between biographical, generational and historical time (Neale, 2012, p.1; Neale et al., 2012). As such, QL methods have the potential to offer insights into experiences of young onset dementia which the current body of knowledge described in the previous chapter does not; a perspective which explores individual transitions in the context of embedded intergenerational relationships and against the backdrop of broader social change.

Prospective QL research designs follow individuals or groups over a period of time and entail repeated waves of data collection. These designs have been used effectively in several complex intergenerational family studies as part of the ESRC Timescapes project (Neale et al., 2012). For example, the 'Work and Family Lives' study (MacLean & Harden, 2012) which sought to understand children's and parents' perspectives on family leisure time, the ongoing 'Intergenerational Exchange' study (Hughes & Emmel, 2012), which is exploring caring relationships between low-income grandparents and their grandchildren and the 'Men as Fathers' study (Henwood & Coltart, 2012), which aimed to illuminate the intergenerational transmission of fathering identities.

A prospective QL study design, then, is the ideal methodological choice for a longitudinal study on younger people with dementia and their families and friends which aims to explore transitions and continuities within and across generations. Charmaz's work (1991, 2002) has done much to illuminate changes in how individuals contend with chronic conditions over time, yet transformations in other family members and friends as a result of dementia have been paid scant attention (Karner & Bobbitt-Zeher, 2006). This study aims to gain insights into such transformations through the use of a QL research methodology.

Multiple perspectives within family research

Conducting research with several people who have interpersonal relationships raises pertinent epistemological questions about whose story is being told (Ribbens McCarthy, Holland & Gillies, 2003a; Barnard, 2005; Warin, Solomon & Lewis, 2007; Harden, Backett-Milburn, Hill & Maclean, 2010). As Perlesz and Lindsay (2003) discovered in their study of families where one member had experienced a traumatic brain injury, individuals can construct differing meanings of events and experiences, and while multiple, often divergent, perspectives generate richly textured data, it is incumbent upon the researcher to make decisions about how such diversity can be represented.

The analytic choices made by researchers are contingent upon their epistemological position and the nature of the knowledge they claim to generate. Drawing upon Ribbens

McCarthy et al. (2003a), Harden et al. (2010) identify a continuum ranging from an objectivist position, where the research question aims to uncover factual accounts of family experiences, to a postmodern relativist stance, where each individual has their own truth. Both extremes of the spectrum, Warin et al. (2007) argue, are problematic; purely objectivist positions are underpinned by a naïve realist ontology, where an external reality obeying natural or social laws can be observed and measured (Blaikie, 2007) and relativism, where all subjective accounts are viewed to have their own 'truth', can result in bland descriptions of a '*cacophony of voices*' (Warin et al., 2007, p. 124) with no attempt at interpretation or analysis.

The epistemology underpinning this doctoral research falls part way along this spectrum. Consistent with the previously explicated theoretical frameworks of family practices (Morgan, 2011) and family displays (Finch, 2007), where families are not viewed as stable units with their own inherent unified truth, but as fluid and evolving sets of relationships, this research explores how understandings are negotiated intersubjectively over time. While closer to the relativist point of the continuum, the research will not merely present descriptive accounts but will produce a coherent, theoretically-informed analysis that interweaves the complexities of concordant and discordant accounts, offering a '*bird's eye view*' (Ribbens McCarthy et al., 2003a, p.15) of processes occurring within families where one person has young onset dementia.

A crucial aspect of representing complex qualitative data is to recognise and acknowledge the ways in which the researcher's positionality influences the production and presentation of knowledge. However, while the importance of reflexivity is widely recognised, the ways in which reflexivity can be operationalised within qualitative research are rarely explicit. In addition, the researcher may not have developed a high level of self-awareness until time has elapsed following the completion of a study; the extent to which researchers can be aware of their positionality during studies is, therefore, questionable, leading some to suggest that '*degrees of reflexivity*' may be a more appropriate way of conceptualising the reflexive process (Mauthner & Doucet, 2003, p.425).

In QL research, the issues of reflexivity are compounded by the evolving nature of the researcher's ontological, epistemological and theoretical assumptions over the duration of the study. Longer term connections with participants facilitates the development of trusting relationships; however, the more involved with our participants' lives we become the more complex and arguably less perceptible our effect on the production of knowledge; similarly, as participants acquire knowledge of the personal and social location of researchers the accounts given in interviews may be more greatly influenced by their assumptions about what we want to know (Warin et al., 2007).

Accepting Mauthner and Doucet's (2003) point that reflexivity, while desirable, may be only partial, I will attempt a self-conscious reflection on how my own ontological and epistemological orientations, and my evolving relationships with participants, have shaped, and continue to influence, the research process. This reflexive practice will be explicated at the end of this chapter.

Applying the case study approach to family research

While there is no consensus on the definition and usage of case studies (Anthony & Jack, 2009), they have been widely used in sociology and other disciplines as a method of understanding how groups, individuals or institutions experience social phenomena (Henderson, Holland, McGrellis, Sharpe & Thomson, 2012). However, while recognised as a useful method to develop in-depth knowledge of particular social circumstances, doubt has been cast as to their wider resonance and the extent to which generalities can be derived from the uniqueness of individual cases (Stake, 1994).

According to Inglis (2010), a concern about generalisability is the foremost reason case studies have been marginalised as a method within sociology. Thick descriptions, he suggests, have been seen as intriguing but as having little currency in terms of generating wider understandings of societal processes, being perceived as neither representative of populations nor theoretically complex. Yet, he argues, some highly significant contributions to sociological thought have originated from case studies (e.g. Goffman, 1961; Whyte, 1969).

Inglis proposes that careful analysis of individual cases with the use of appropriate theoretical frameworks, a technique he entitles '*sociological forensics*' (p. 507), offers a way of learning about the general from the particular. He argues that:

'given the principle that elements of the whole can always be found in the part, when these clues are carefully analysed, they can provide insight into the wider social structure... each case study contains clues, episodes or events which illuminate micro-macro connections' (p. 514-515; 519)

The question that arises with respect to this study is to what extent accounts of five individual families experiencing young onset dementia can shed light on processes occurring within other families where the same condition exists. I argue here that while individual families are unique, bringing the cases into conversation with one another has the potential to reveal aspects of relationality within other families facing a similar experience.

Using a similar logic, Bertaux and Delacroix (2000) suggest that processes that occur within unique families have the potential to generate understandings that have resonance with other families:

'one way to look at families is to consider them as microcosms: small worlds, each one worth exploring, deserving description for its own 'sociographic' sake, but each one also capable of enclosing some sociological pearl - some vivid evidence of a given process whose awareness might illuminate thousands of other cases' (p. 83)

Case studies in qualitative longitudinal research

In recent years QL research has experienced renewed interest as a method of generating richly detailed processual accounts of social life (Holland & Edwards, 2014). However, methods of analysing and representing complex QL data sets have rarely been elucidated (Henderson et al., 2012). A notable exception is Thomson (2007, 2010), who has described the creation of family case histories as methods of condensing the complex temporal nature of the data. Preferring the term 'case history' over 'case study', Thomson argues that case histories aim to create a descriptive and explanatory account of events and processes that occur over time in the specific social and temporal context.

According to Thomson, the case history approach in family QL research enables a processual focus, creating accounts of unfolding relational transitions and continuities over time through drawing attention to key events, recurrent motifs, trajectories and turning points. Although unique family case histories cannot be directly compared, she suggests, bringing them into conversation with one another provides further insights into the processes experienced within the families.

The use of a QL family case study approach to explore the relational experience of young onset dementia has great potential to both privilege the uniqueness of family experiences yet also, through juxtaposition, uncover cross-case commonalities and differences.

Generalisability

A consideration of the methodology of a study would be incomplete without a discussion of generalisability. Generalisability in qualitative research is evidently of a very different nature to the probabilistic generalisations made by quantitative researchers (Popay, 2003), where it is proposed that statistically significant findings from a sample representing a population can be said to hold true for the whole population. The notion of generalisability of qualitative research is contentious, and hence no consensus exists (Chenail, 2010); for instance, scholars with a post-modern stance, Chenail argues, would reject any form of generalisation.

The concept of generalisability in any form of research is underpinned by the nomothetic-idiographic continuum (Fingeld-Connett, 2010). The goal of nomothetic science is the discovery of universal laws to explain and predict phenomena and is associated with objectivity and the natural sciences. In contrast, idiographic science is the study of the particular and is more aligned with subjective inquiries within the humanities. The distinction between the two is sharply felt in the social sciences, which recognise the contingent meaning-making nature of human beings while also assuming that there are regularities in social life (Schwandt, 1994; Zhao, 1996). Sandelowski, Docherty and Emden

(1997), Mason (2002) and Green and Thorogood (2009) concur that naturalistic or logical generalisations can and should be made from qualitative studies.

Conducting research with people with dementia

Bartlett (2012) has noted that the entitlement of people with dementia to participate in research as active agents rather than passive subjects is now '*generally accepted wisdom*' (p. 1717). However, the body of research that privileges the experiences, views and opinions of people with dementia is still relatively limited (Cowdell, 2006; Nygård, 2006) compared to the more widely available proxy accounts of their informal or paid carers; a methodological approach that has been criticised by several authors (e.g. Cotrell & Schulz, 1993; Wilkinson, 2002; Hellström et al., 2007).

The increasing rejection of the view that people living with dementia are unable to express their views or participate in research (McKillop, 2002; McKillop & Wilkinson, 2004; Sabat, 2005) has led academics to assert that the question that needs to be addressed is not whether but how people with dementia can be active agents in research (Hellström et al., 2007). It has been suggested that the inherent power imbalance that exists between researchers and researched could be exacerbated by the impairments experienced by people with dementia (McKeown, Clarke, Ingleton & Repper, 2010), and it therefore seems particularly apposite to democratise the research process (Nind, Wiles, Bengry-Howell & Crow, 2013) through enabling the person with dementia to take as much control of their involvement as possible (Bartlett, 2012).

Offering a range of methods of engaging with the research was the approach adopted in this PhD study, consistent both with the principle of democratisation and with the pluralist use of method espoused in QL research (Thomson, 2012). Unstructured or semi-structured interviews were likely to remain the primary method of eliciting data, yet, since interviews have the potential to be disempowering for people with dementia, in some instances acting as a '*cruel reminder*' of linguistic and memory difficulties (Hubbard et al., 2003, p. 356), other methods of engagement were offered, for example photo, audio or written diaries, blogs, graphical representations or artwork, thereby enabling the

participant to engage in their preferred way. Collecting observational data has been recommended by several writers (Bond & Corner, 2001; Sabat, 2005; Nygård, 2006) and field notes detailing significant occurrences were maintained to supplement data collected through other methods.

The person with dementia was also able to choose where the research interactions took place (Clarke & Keady, 2002), and whether they would prefer be interviewed alone or with another person. While there is an abiding yet questionable assumption in qualitative research that individual interviews are preferable to joint ones (Bjørnholt & Farstad, 2014), and some researchers have found joint interviews where one person has dementia challenging (Pesonen, Remes & Isola, 2011), it is crucial for the person with dementia to feel safe and supported in an interview situation (Pratt, 2002). Moreover, since this research was underpinned by a symbolic interactionist perspective, which views the self as relational (Mead, 1934), joint interviews could give direct access to observe real-time processes of meaning-making shaped by social interaction, which may not be obtained in individual interviews.

Hellström et al.(2007) and Pesonen et al. (2011) have suggested that attention needs to be given to the development of 'dementia-specific' research methods. However, there is a tension between being enabling, and seeing people with dementia as being 'other' to ourselves (Clarke & Keady, 2002; Harris, 2013). Perhaps a more democratised person-centred approach to use of methods in qualitative research in general might be appropriate, yet there is, as Nind et al. (2013) note, a difficult balance to be struck between giving more control to the participant, and meeting the standards of rigour required by academia.

There is a strong commitment throughout the study to maintain the personhood of the participants with dementia. Establishing sincere and respectful research relationships is clearly a crucial aspect of conducting a longitudinal study with people with dementia, requiring empathy, sensitivity and consistency (Pesonen et al., 2011). Indeed, Cowdell (2006) suggested that the researcher's manner and interpersonal skills are of greater significance in conducting research with people with dementia than the style of the interview.

Bond and Corner (2001) noted that one of the issues faced by researchers is that they have no real knowledge of the experience of dementia, and, moreover, any personal experience they may have had with people with dementia may even serve to furnish them with presuppositions that could be misguided due to the heterogeneous nature of the condition (Hubbard et al., 2003; Hellström et al., 2007). The tremendous variability in impairments between people with dementia led Hubbard et al. (2003) to advise that researchers should use imagination to create a '*repertoire of strategies*' (p. 359) for each participant in the research.

Taking time (Cotrell & Schulz, 1993; Clarke & Keady, 2002), being clear about the purpose of your presence (Nygård, 2006), and developing trust, warmth and empathy (Bond & Corner, 2001; Hellström et al., 2007) are all vital to laying the foundations for effective research relationships. There was also a general consensus on the need to listen attentively (Pratt, 2002; Pesonen et al., 2011), to engage in small talk when appropriate (Nygård, 2006) and to be vigilant for and responsive to verbal and non-verbal signs of stress and fatigue (Hubbard et al., 2003; McKeown et al., 2010). All of these recommendations shaped the way the data collection was conducted throughout the study. Accordingly, I allowed half a day for each interview, and typically spent between one and three hours at participants' houses. I interspersed interviews with conversations about general topics such as sport whenever I felt that the person with dementia's attention was waning, and I remained alert to signs of tiredness. On one occasion, for instance, one of my participants suddenly looked grey and fatigued. I asked if she would like to stop the interview and she said she would like to pause briefly while she had a drink, during which time we talked about other topics. The pallor soon disappeared and, after re-establishing consent, we resumed the interview.

Icebreakers

There are other aspects of researching people with dementia which are more contentious than those described above. For instance, some authors recommend an ice-breaker; Hellström et al. (2007), for instance, gave a gift of a small flower to their participants, which was felt to be appropriate in the context of Swedish culture. Some social scientists

may see this as an inducement, and argue that it may place a tacit obligation on people to comply with the study (Oliver, 2010), yet, in the context of longitudinal research, when participants are asked to make a considerable commitment to a project, a small gift may be appropriate (Neale & Hanna, 2012). The participants in this study were each given a small houseplant as an ice-breaker in wave one of the study and again at the end of the final interview as a thank you gift. This seemed appropriate to me, given my awareness of the commitment being asked of my participants and the likelihood that I would be offered hospitality in people's homes and would wish to reciprocate in a material way. The modesty of the gift did not seem to create a feeling of obligation on behalf of the participants, but I remained attuned to that possibility and was prepared to consider how the gifts might impact on the data collection process. The plants also served as a reminder of the study to participants in between waves of data collection, and as a topic of conversation at the beginning of subsequent interviews.

Language and terms of engagement

Another area on which there is some disagreement in the extant research methodology literature is whether to mention the term 'dementia', a term which unfortunately still carries stigma, during research encounters, given that some participants may not have been informed of their diagnosis or may have forgotten it. Bartlett and Martin (2002), Hellström et al. (2007) and Pesonen et al. (2011) opted only to use the word dementia if the participants themselves used it, using instead phrases like 'memory problems' or 'problems finding the right words'. McKeown et al. (2010), however, argue that the commitment to honesty in qualitative research should perhaps be extended to include openness about diagnosis, and questions could be raised about whether consent is informed if the diagnosis is not referred to. Conversely, Cowdell (2006) suggested that it is incumbent on the researcher not to reveal the diagnosis to the participant with dementia, and in accordance with that view, great care was taken during this research not to make such a disclosure. Although all the participants would have entered the study via their membership of a community organisation that has young onset dementia or young dementia in the title, and therefore will at least at one time been aware of their

diagnosis, it is possible that they have forgotten and thus the term was not used. I chose to adopt whichever term or phrase they used to describe their condition, whether that be 'dementia' or a condition-specific term. While it could be argued that there is a certain level of deception in this approach, this does not outweigh the risk of distress to participants.

In Chapter Four I alluded to debates concerning the use of the term 'family', which can be perceived to privilege the heteronormative nuclear family and disadvantage other forms of interpersonal relationships. Accordingly I chose to remain sensitive to and to adopt my participants' relational terminology during interviews.

Interviewing people with dementia

In conducting interviews with people with dementia, it is accepted that some abilities will be affected, for example memory, linguistic skills, reasoning or making judgements (McKeown et al., 2010), however it is vital to avoid condescension and to make allowances only where necessary (McKillop, 2002). Asking people with dementia to provide detailed factual accounts may demonstrate insensitivity to the difficulties they face (Cotrell & Schulz, 1993; Pratt, 2002; Hellström et al., 2007); but as Sabat (2005) has argued, people's diagnoses and scores on cognitive tests bear little relation to their ability to talk about their experiences, emotions and needs. Nygård (2006) recommends asking concrete rather than abstract questions, keeping interviews short and allowing breaks for small talk to give participants time to relax. Dealing with silences while a person searches for the right words can also be challenging; Hubbard et al. (2003) felt the need to interject when someone was struggling, while Killick (1999) and Pesonen et al. (2011) opted to tolerate silences, allowing respectful time and space for the participant to respond.

In this research, great care was taken to enable the participants with dementia to set the agenda and pace of the interview (Nygård, 2006; Hellström et al., 2007), facilitating a sense of achievement (Pesonen et al., 2011) and encouraging the contribution of reflections on the process during or following the interview (McKillop & Wilkinson, 2004).

In the research I chose to tolerate silences in the main as I felt offering words might be perceived as condescending, and also may interject my own presuppositions about what the participants were seeking to express. Sometimes another participant would contribute words and I remained alert to see whether the offered words captured the meaning of the person with dementia. On rare occasions participants asked me to assist in their search for words and I complied with their wish, offering a selection of words to try to facilitate their meaning to be expressed.

Reflexivity has been described as an essential element of rigour in qualitative research (Johnson, 1999) and perhaps its importance is magnified yet further when research is being conducted in complex and sensitive areas. Critical reflection with supervisors is crucial to ensuring this research is conducted with sincerity, responsibility and authenticity. McKeown et al. (2010) note that, while many people with dementia find research interviews affirming and therapeutic, the potential for exploitation exists. Tee and Lathlean (2004) argue that in research with vulnerable people, it is essential that the researcher and supervisors monitor the research encounters to explore and resolve any unintentional power imbalances, thereby maintaining a democratised research process.

While a crucial aspect of any qualitative research, reflexivity is perhaps of even greater significance when conducting research with families. However heterogeneous the concept of family, and the meanings ascribed to it, there is little doubt that it carries an emotional resonance for researchers (Jamieson et al., 2011). Reflecting on how knowledge about families is created and produced is, therefore, a crucial aspect of the methodological approach to this study.

Maintaining research relationships over time

Longitudinal studies require careful management of research relationships over time (Neale & Hanna, 2012; Neale et al., 2012). Although Cowdell (2006) suggested that repeated interviews with people with dementia did not necessarily create more insightful data, many researchers (e.g. Cotrell & Schulz, 1993; Clarke & Keady, 2002; Pratt, 2002; Nygård, 2006; Personen et al., 2011) have extolled the benefits of longitudinal study

designs. Certainly one-off interviews offer less potential to capture change over time in the face of a progressive condition; equally they do not facilitate the development of trusting research relationships to the same extent. However, as Cowdell (2006) notes, terminating these long term relationships has been rarely discussed in the dementia research literature, although it has received attention in qualitative longitudinal research more generally (Thomson, 2012). Hellström et al.(2007) felt that there was no easy solution to the problem of disengagement, but suggest that maintaining honesty about withdrawal throughout the project is fundamental to a sincere research relationship. I reminded my longitudinal participants at each encounter about the study design and when the final interview would take place. Although early in the study we had considered doing a joint feedback session and lunch with all the families, considerations of anonymity and the geographical distance between the families made such an event too difficult.

Pesonen et al. (2011) found, in their longitudinal study, that involving a family member in the research process was a useful means of reminding the person with dementia of forthcoming research appointments. Involving a third party in research with people with dementia is common (Cowdell, 2006), yet the capacity in which they are involved is often more complex than merely assisting with the organisation of appointments. Hellström et al. (2007) were concerned that the people with dementia in their study were sometimes persuaded to participate by their spouses and Nygård (2006) advises against using the carers' perspectives to validate the accounts of people with dementia, suggesting rather that their perspectives can be used to '*broaden the view*' (p.105).

There is clearly a need, in a study such as this, to balance paternalism and autonomy (Tee & Lathlean, 2004). A certain level of protection for the people with dementia is desirable, whether that is from family members or an organisation, to minimise anxiety and to enable the person to feel safe, but complex processes occur within families regarding who takes part in interviews and why they do so, which researchers may only be partly aware of. In this study, it emerged during the final interview that a granddaughter initially took part to please her grandmother, although she derived satisfaction from being involved. In another family, there was a suggestion that participating in the research was an opportunity to communicate difficulties caused by dementia to other family members,

and that a spouse encouraged his wife to overcome anxiety about new situations to participate. Thus the research process may be intimately connected with the ways in which people make sense of and live with dementia.

Informed consent

The issue of informed consent in any form of social research, while seemingly straightforward, is complex (Israel & Hay, 2006). When research is conducted with people with dementia, whose memory, reasoning, and judgement-making ability may be impaired, establishing participants' informed consent in a way which satisfies the demands of ethics committees is particularly complicated. Unsurprisingly, this issue has received considerable attention in the literature; Hellström et al. (2007) have described the current research governance model of informed consent as universalistic, exclusionary and cognitive, and assert that a model for conducting research with people with dementia should aim instead to be particularistic, inclusive and context-relevant. Dewing (2007) also rejects competency-based informed consent for people with dementia, proposing instead a model of 'process consent', whereby the researcher establishes a basis for consent and continually monitors consent throughout the fieldwork, being vigilant concerning the person's state of well- or ill-being and constantly critically reflecting on their own practice. While Dewing's approach is designed for people with very limited capacity, and this research only includes people with mental capacity, there are certain principles which can be adopted from Dewing's model, in particular the revisiting of consent at every data collection point and, if necessary, during a single research encounter. Such practice is common in many forms of qualitative longitudinal research, with the caveat that reminders can prove an irritant and have the potential to adversely affect research relationships (Neale & Hanna, 2012).

Ethical approval for this study was granted by the University's Research Ethics Committee (REC) on the basis that consent forms are completed and signed by all participants at each research encounter. It was recognised that due to the longitudinal design of the study and the unpredictable progression of dementia, capacity to consent could be lost over the course of the research. I sought advice from the Social Care Research Ethics

Committee Co-ordinator who indicated that people who have lost capacity would have to be excluded from the study at the point at which loss of capacity was established, unless approval is then sought and acquired from the Social Care Research Ethics Committee to continue their involvement. Participants were asked on the consent form whether any data previously gathered can still be used for research purposes should loss of capacity occur before the end of the study. None of the participants lost capacity over the twelve-month data collection period. The REC-approved consent forms and information sheets can be located in Appendix C and Appendix D.

Researching children and young people

Involving children and young people in research invokes similar ethical complexities to including people with dementia as participants. In both instances, there is a clear tension between paternalism and the recognition of their status as active social citizens with the right to express their knowledge as experts on their own lives (Balén et al., 2006; Notko et al., 2013). According to the United Nations Convention on the Rights of the Child (1989), which the UK has ratified, the state is required to :

'assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child (article 12).... the child shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of the child's choice' (article 13)

It is incumbent, then, upon childhood researchers to facilitate children's and young people's voices to be expressed where possible rather than to accept proxy accounts of parents or other adults (Christensen & Prout, 2002). Indeed, Balén et al. (2006) point to a substantial body of research that suggests children's perspectives are often different to and more complex than adults might imagine. However, there are ethical sensitivities to negotiate when researching children and young people. In accordance with the provisions of the Family Law Reform Act (1987), sixteen and seventeen year olds are assumed to be competent to make consent decisions unless there are grounds to doubt their capacity to do so (Allmark, 2002).

Allmark (2002) argues that there are three ethical considerations that need to be addressed regarding scientific validity, welfare and rights. Firstly, he argues, research on children cannot be justified if it is of poor quality and unlikely to contribute to new knowledge; secondly, that the potential risks and benefits of the research need to be evaluated, and thirdly that the children's rights regarding confidentiality and consent are considered. The growing recognition of the status of children as social actors has created a debate in social research as to whether children are able to consent to participation in research, or whether proxy consent is required from parents or guardians (Balén et al., 2006).

One person, Lauren (name changed to protect identity), under the age of sixteen participated in the study. In this instance, a child-parent-grandparent-researcher relationship was facilitated to negotiate parent informed consent/ permission and child informed assent (Lambert & Glacken, 2011). Lauren chose to be interviewed alone and interviews took place in her grandparent's house. The grandparents occasionally entered the room during the interviews to answer the telephone or to retrieve items but did not involve themselves in the conversation.

Information sheets and consent forms were given to her mother, and Lauren was provided with an age-appropriate information leaflet, which I created and young people known to me checked for clarity. Both Lauren and her mother were asked to sign consent forms. This process acknowledges the parental role of protection (Allmark, 2002) while also validating a young person's right to be heard (United Nations, 1989) and to be recognised as an active citizen with the right to self-determination (Lambert & Glacken, 2011).

Including a young person in the study accorded me additional responsibility. Age-appropriate verbal information was provided in addition to written information, and I talked through the information leaflet prior to the first interview to ascertain and respond to any further information needs. I also showed Lauren my Disclosure and Barring Service Check and university identification in advance of our first interview, in the hope that having to prove my credentials to her may reduce the power differential between us while reassuring her of my professional status. Lauren was assured of several

key aspects of her involvement: that participation was voluntary and there are no adverse effects to refusing to participate; that she could pause or withdraw at any time without explanation; and that she was under no obligation to consent as a consequence of their perceptions of either parent, grandparent or my expectations. Great care was taken to emphasise confidentiality unless it related to a safeguarding issue, in which instance I informed Lauren that I would discuss strategies with her to involve relevant authorities. No safeguarding issues arose in the interviews. I reminded Lauren of her rights before each interview.

Lauren was asked for her reflections on each research encounter. Christensen & Prout (2002) argue that this dialogue is essential both for increasing the quality of the researcher's critical reflection and also to demonstrate respect for the child's personhood.

Researching families

Attention needs to be paid to the ethical issues of involving families in research. Naturally, with a study that explores change over time, a key focus of the research was the exploration of what Finch (2007) terms the '*fluidity of family life*', by which she was referring not only to membership changes (Smart & Neale, 1999), but to changes in relationships and identities:

'the fluidity of family life is not defined by shifting membership so much as by the continually evolving character of the relationships – how individuals talk to each other, act towards each other and the assumptions on which their relationships are conducted' (p.69)

In seeking to illuminate changes in families regarding a complex and sensitive topic such as dementia, methodological and ethical issues need to be considered (Gabb, 2008); the concept of familial privacy in Western societies remains potent (Gabb, 2010), and maintaining confidentiality both within and beyond the family is vital (Gabb, 2008; MacLean & Harden, 2012).

An issue that is perhaps considered less often in social research is the effect of the study upon the researcher, and how that may influence the way the findings are reported. In QL research, it is acknowledged that the researcher's life will not remain unchanged (Neale et al., 2012), and Gabb (2010) takes this observation a step further by drawing attention to how this may affect the way the researcher represents family life:

'the researcher inevitably becomes embedded in the personal worlds of those being researched...presenting 'unfavourable' data on families who gave so much of their time and themselves to our research can feel like a betrayal'
(p.461/473)

A balance needs to be achieved, she suggests, between honouring the trusting relationship that develops in longitudinal family research, and representing the richness and complexity of data, even when that data reveals contentious aspects of family lives. The analysis and presentation of data, therefore, has been discussed carefully with supervisors and forms a key element of the researcher reflexivity strategy.

Study design

The aim of the proposed research is to explore young onset dementia as an evolving family and friendship network experience, and to gain insights into the perceptions of support services which could inform future service development.

An exploratory approach has been adopted which is congruent both with QL research and a symbolic interactionist perspective (Blumer, 1969). Originally designed to be conducted over nine months with a group meeting at the end, the fieldwork period was extended to twelve months to develop broader insights, with four waves of research encounters planned at months 0, 4, 8 and 12. The rationale underpinning the frequency of the waves was to create a design sensitive enough to capture change. However, on reflection, it was felt that due to the complexity of the analysis required between waves, and the desire not to be overly intrusive, three waves timed at months 0, 6 and 12 would be more appropriate.

Research questions

Congruent with Blumer's (1969) methodological approach, it was anticipated that the inquiry would evolve as areas of interest emerge over time. Therefore the following questions were not viewed as intractable objectives, but as themes worthy of exploration:

- **How does young onset dementia affect families and friends?**
- **How does the experience differ for family members of different generations?**
- **How does the experience evolve over time?**
- **What are their experiences of formal support?**
- **What are their perceptions of the kinds of help that could make a positive difference?**

Mason (2002) encourages researchers to create a chart of their research questions, providing details of the rationale, potential data sources, ethical and logistical considerations. These are described in Table 1.

Table 1: Research Questions, Data Sources and Ethical Considerations

Research question	Data sources and methods	Justification	Practicalities, challenges and ethical considerations
How does young onset dementia affect a family?	Unstructured and semi-structured interviews Graphical representations Field notes Self-reporting through blogs, diaries etc	Data sources will provide accounts of the effects of the condition over time on their lives, identities and relationships	Difficulties of interviewing members of the same family separately - generational power dynamics, participant concerns about what is being said by other family members. Crucial to create trusting relationships Network confidentiality needs to be ensured Risk of participants becoming upset Informed consent - use model of process consent
How does young onset dementia affect friendships?	Unstructured and semi-structured interviews Graphical representations Field notes Self-reporting through blogs, diaries etc	Data sources will provide accounts of how the condition has impacted friendships and how meaning of condition is negotiated in friendships	Participant concerns about what is being said by others in individual interviews Network confidentiality Risk of participants becoming upset
Does the experience differ for family members of different generations? If so, how?	Unstructured and semi-structured interviews Graphical representations Field notes Self-reporting through blogs, diaries etc	A comparison of accounts from different data sources will help to build up a picture of whether there are any intergenerational differences, and if so, the nature of them	May be time-consuming and complex analysis

What experiences of formal support have families and friends had?	Unstructured and semi-structured interviews Self-reporting through blogs, diaries etc	Need to gain knowledge of current service provision in the area to provide context to understand how people access, use and perceive services	Risk of participants becoming upset Informed consent - use model of process consent
What are participants' perceptions of the kinds of help that could make a positive difference?	Unstructured and semi-structured interviews Self-reporting through blogs, diaries etc	Participant accounts will enable a picture to be built up of gaps in service provision and will highlight areas that can be improved. These findings will be disseminated to relevant audiences with the aim of contributing to debate/ discussion on service provision	Risk of participants becoming upset Informed consent - use model of process consent

Refinement of research questions over time

As Blumer (1969) contends, a symbolic interactionist enquiry sharpens as the study progresses and the researcher becomes more familiar with the experiential world of the participants. Direct engagement with this world, he argues, gives the researcher:

'a secure bearing so that he knows the questions he asks of the empirical area are meaningful and relevant to it, that the problem he poses is not artificial, that the kinds of data he seeks are significant in terms of the empirical world'
(p.42)

The research questions, then, while still related to the original areas of interest, become more focussed as engagement with the participants' worlds deepens. In this research, the iterative relationship between emerging empirical themes and theoretical frameworks shaped and refined the original research questions to those below:

- How do people within intergenerational families make sense of young onset dementia and what effects does previous experience of the condition, if any, have? How is the past, present and future constructed? How are people influenced by, or influence the social movement of dementia? What is the significance of support group membership to the sense-making process?
- To what extent and by what processes do people within different generations 'belong' to the experience of dementia? What bearing does relational history have on the experience of dementia, and by what processes does information about dementia flow within families? To what extent do people normalise dementia and protect each other from the effects of the condition?

Sampling Strategy

For logistical reasons, this exploratory longitudinal study aimed to involve a small purposive sample of families and support networks, ideally between five and ten intergenerational families. It was important to recognise that sustaining a sample can be challenging in longitudinal research (Patrick, 2012) and that therefore researchers should,

as a precautionary measure, enrol more participants than they need to mitigate against sample attrition (Saldaña, 2003).

Accessing a sample of people who have a rare and difficult to diagnose condition is challenging (McKeown et al., 2010). These issues are compounded by asking families to be engaged in the study for a year when they are experiencing a condition with an unpredictable course. In addition, while the dissemination strategy of the findings will incorporate policy-making and service provision domains, it is unlikely that participants would receive any direct benefits from changes to services themselves. Given these potential barriers to recruitment, a decision was made to create collaborative partnerships with two third sector organisations that could facilitate access to potential participants. Although concerns have been expressed regarding the dangers of paternalism when using gatekeepers in dementia research (Bartlett & Martin, 2002; Cowdell, 2006), I argue that this recruitment strategy was appropriate since the organisations could provide support for participants if they became distressed as a result of the research process.

Relationships were created with a charity in the south of England that provides support services for young people with dementia, and with a young dementia support group set up by AgeUK in the north of England. Project information sheets were designed and circulated to these organisations and comments made were subsequently incorporated in redrafts of the documentation. Creating collaborative partnerships such as this at the outset of the project facilitates the impact agenda of the research, as anonymised findings can be fed back to the organisations which could improve the service for the users through contributing to the evidence base for their practice.

The inclusion criteria for the study are that:

- the person was diagnosed with dementia before the age of 65 years
- they are in a relatively early stage of the condition and have capacity to consent to the research process according to the provisions of the Mental Capacity Act (2005). Should the person lose capacity to consent during the study, approval to continue their participation will have to be obtained from the Social Care Research Ethics Committee

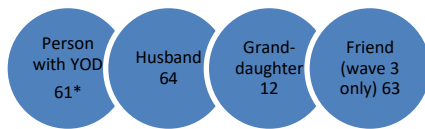
- the person has family members and/or friends who could also be involved in the research. Snowball sampling was used to identify and recruit family members and friends as the study progressed

Recruitment

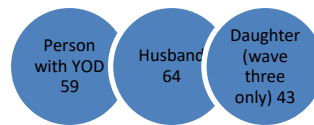
In practice recruiting and retaining a sample proved challenging. Consistent with the terms of my ethical approval, I attended a meeting of the group in the north of England to explain my study. I was not permitted to recruit people in person but left information packs for group members to take home. Within each pack was a reply slip and stamped address envelope. From this group I recruited one family to the study. I arranged to leave further packs with the group at a later date but did not receive any additional responses. Recruiting families for this type of research is challenging; for their family study of young onset dementia, Roach et al. (2013) distributed 120 information packs across ten services in the North West of England and were only successful in recruiting five families, a conversion rate of just over 4%.

I received a list of twelve possible participating families from the charity in the South and felt that I would be able to recruit sufficient families from there. However, on further contact, four of the twelve families decided not to take part in the study. One further family wanted to participate and a first appointment was made; however, as they were in the process of moving house they wanted to delay the start of their involvement for several months which was not feasible because of the timescale of the study. Three further families requested a second information pack, then on follow up contact had decided they did not want to be included. Ultimately four families agreed to be included, although not everyone within the family wanted to participate. The make-up of the samples is detailed below:

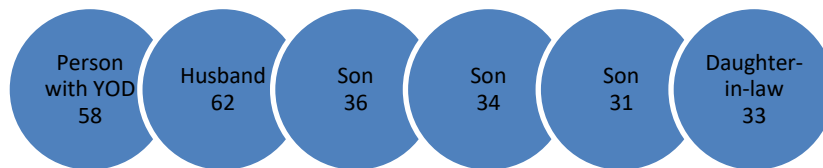
Family One:



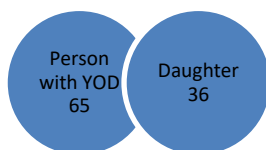
Family Two:



Family Three:



Family Four:



Family Five**:

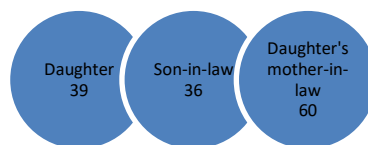


Figure 1: Study Sample

YOD - young onset dementia

**All ages stated are at the time of the Wave One interview*

***When Family Five were interviewed during the first wave, the person with young onset dementia was unfortunately too unwell to participate in the interview.*

Sample retention

Retaining a sample in QL research is known to be difficult (Patrick, 2012; Farrall, Hunter, Sharpe & Calverley, 2016). While all families participated in Wave One of the data collection process, unfortunately Family Four and Family Five did not continue their participation in the study.

I had made the decision to contact families a maximum of three times when arranging subsequent interviews. Acknowledging that all contact details such as physical and email

addresses and mobile and landline numbers may change between interviews, and that lack of a response might therefore indicate a delivery failure rather than a lack of desire to continue in the study, I opted to use three different methods of contact. Family Four did not respond to attempts to arrange the second interview via email, voicemail and letter, and it was presumed therefore that they no longer wished to participate in the study.

Of all the families, participants from Family Five had shown the most enthusiasm for the study during the first interview. They expressed pleasure at taking part in the research, and noted afterwards that it had been very helpful to have the opportunity to describe some of their experiences with someone who they felt would understand. They indicated a wish to continue in the study and I did not anticipate any difficulties arranging and completing the second interview. However, around half way on my three-hour drive to the interview, I received a voicemail saying that they needed to rearrange the appointment because a family member had given birth prematurely. I subsequently tried to rearrange the interview twice but both times they cancelled it due to other commitments. Finally I asked whether it would be easier for me to send a schedule of questions with a stamped addressed envelope so that they could write their thoughts and experiences down at their own convenience. I devised a list of open-ended questions based on themes from their first interview. The participants agreed that this would be more suitable for them and they would be happy to do this but they did not return the schedule. Knowing the various stresses the family were experiencing I did not feel it was appropriate to continue to ask for another interview or the returned schedule at that time, and decided instead to contact the family again by letter at the time of the third wave interview. I included an opt-out form with a stamped addressed envelope. They returned the opt-out form to state that they did not want to continue their participation but were happy for me to use the data from the first interview.

Three families (Families One, Two and Three) completed three waves of interviews.

Data collection

The primary means of data collection in wave one was unstructured interviews. However, in keeping both with the commitment to empowerment, and the creative use of method espoused by symbolic interactionists (Blumer, 1969) and proponents of QL research, participants were encouraged to engage with the study in their preferred ways. For example, options included written, audio or photo diaries, a private blog on the study website (<http://young-onset-dementia.com>), graphical representations or other means of expression. Thomson (2012) has argued that the creative use of data collection methods can facilitate interaction within a different affective register, enabling the unsaid to be expressed. This may be particularly important for people with dementia, who may prefer other means of self-expression to a semi-structured interview.

Likewise, any study participants, but perhaps particularly children, adolescents and young people may prefer to write a blog, send texts or create a video rather than be interviewed. Offering a menu of engagement options permits people to make choices on how they wish to be involved, enabling me to capture data in formats meaningful to study participants. Honouring the personhood of the participants through enabling choices was a key focus of this research, and offering choices of engagement was deemed important.

Interestingly, although two participants initially showed interest in writing blogs, ultimately all participants opted solely to be interviewed. The reason given for this choice was that discrete events spent discussing young onset dementia were preferable to the more frequent attention required by blogs or diaries. However, the person with dementia from Family One periodically provided material from other dementia-related activities she had been involved in, such as radio or TV appearances, and a written version of her experience entitled '*My Alzheimer's Journey*' which she used to give talks at events to raise awareness of young onset dementia.

Wave one data collection

During Wave One, participants were encouraged to tell their story of the diagnosis of young onset dementia and their experiences of how the condition had affected their lives. In order to enter the social worlds of the participants with an open mind, and not to impose my perspectives on the participants' experiences, Wave One interviews were largely unstructured and questions were kept to a minimum so that the experiences, expressed in terms meaningful to the participants, could be captured. As Gabb (2008) has noted, enabling families to set the agenda in exploratory research on sensitive topics is important to prevent the researcher from making presuppositions about the significance of events and experiences.

The commitment to enabling engagement choices meant that participants negotiated between themselves who was to be present at each interview. Individual interviews only took place in Family One, where granddaughter Lauren and the person with dementia's friend, Josie, opted to be interviewed separately. In all other cases the participants chose to be interviewed together. However, participants often found opportunities to raise or reiterate issues on a one-to-one basis with me; occurrences such as phone calls, another participant making coffee, two participants talking briefly between themselves or someone leaving the house to collect grandchildren often provided space for a brief individual interview within the group setting. Bjørnholt and Farstad (2014) have noted that there is a general yet unfounded assumption within social research that interviews conducted with individuals are somehow superior to those conducted with spouses or families, however, according to Eggenberger and Nelms (2007), there are several advantages to collecting data from family groups. For example, the synergy of the group setting enables the real-time capture of interactional meaning-making, illuminating how family members engage with each other. Additionally, they argue, there is evidence to suggest that families value the opportunity to share thoughts and feelings about a family member's illness and to become more aware of each other's perceptions, beliefs and concerns. In this sense the boundary between research and therapy can become blurred (Hart & Crawford-Wright, 1999). While I would not make any presumption of having therapeutic skills, creating a space where family members can have a dialogue about an

issue of mutual concern may enable them to negotiate shared understandings and to discuss the most appropriate action to take.

Eggenberger and Nelms (2007) note that interviewing family groups is more challenging than interviewing individuals. Potential problems include: developing rapport with each family member, encouraging quieter members to contribute, and dealing with conflict between family members. Researchers may also experience the '*happiness façade*' (Åstedt-Kurki & Hopia, 1996, p.509) where people perform the best version of themselves as a unit and difficulties are concealed. While it was difficult for me to assess whether such a façade was presented, it was certainly the case in Family Three that more relational tension was described during the final than the first interview. However, I concur with Eggenberger and Nelms (2007) that encouraging quieter members to participate was challenging; for instance, one participant in Family Three would only speak when asked a direct question.

Wave Two

An individual topic guide for each family was created following analysis of data from Wave One, which focussed on aspects of experience deemed important by the participants. These were revisited to gain understandings of changes and continuities since the previous interview. However, utilising this approach on its own would not capture new experiences; therefore each interview commenced with a broad question of changes that had occurred since my previous visit, followed by probing for further information. In addition, issues raised by other families were introduced to try to gain an understanding of commonalities or diversities in experience.

Wave Three

An individual topic guide was again constructed for each family, and the interview commenced with the open-ended question about issues or experiences that had changed since Wave Two. The final interview also provided an opportunity to review some of the

key themes pertinent to each family. Examples of topic guides for Wave Two and Wave Three interviews can be located in Appendix E.

The recursive method of data collection is portrayed in the figure below:

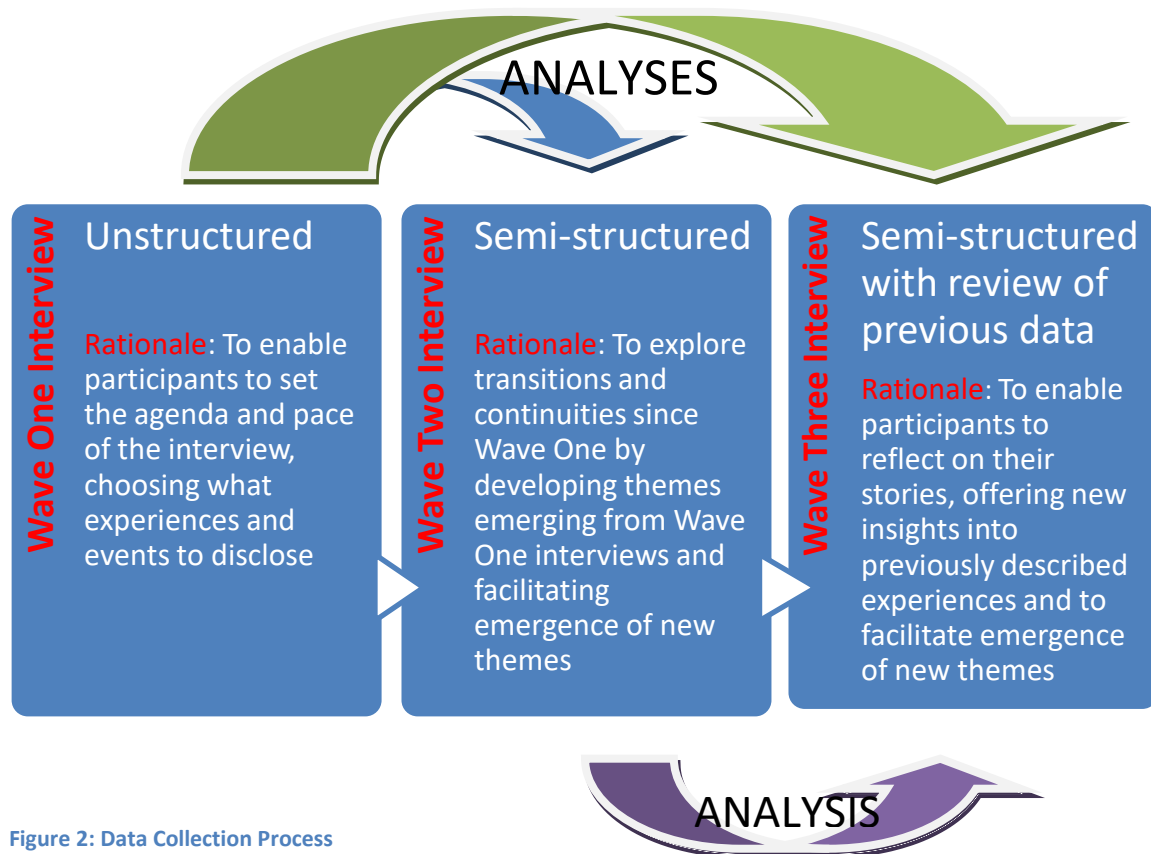


Figure 2: Data Collection Process

Data analysis

Interpreting and representing any qualitative data set is necessarily a complex endeavour for a researcher (Denzin, 1994). However, this complexity is compounded when the data comprises waves of interviews with several participants within a family (Thomson, 2010). Attempting to generate understandings in the context of concordant and discordant accounts, embedded relationships, the subjectivity of the researcher, and the interplay of biographical, generational and historical time requires an imaginative approach to data analysis predicated upon a holistic perspective but enabling cross-contextual analysis.

Despite the increasing interest in QL approaches to understanding the relationship between the micro and the macro (Holland & Edwards, 2014), little has been written about the development of analytic strategies that can be applied to a rich and complex QL data set (Henderson et al., 2012). Drawing on his theatrical background, Saldaña (2003) exhorts the QL researcher to identify a '*through-line*' (p. 150), the most prominent trajectory experienced by an individual over the course of the data collection, and '*motifs*' (p. 128), which are suitable for exploring recursive individual or social experiences in case studies (Saldaña, 2013). Similarly, in endeavouring to make QL analysis less opaque, Thomson (2007, 2010) has described a case history approach which aims to provide a detailed description of the transformational processes experienced over time and to offer explanations as to how and why social action unfolded in the way it did. QL analysis, she argues, transcends framework analysis and coding practices which unhelpfully fracture data. In contrast, QL data, which explores individuals or groups in specific temporal and spatial contexts, should be analysed in ways that retain context while also elucidating the researcher's positionality.

Inspired by her approach, I envisioned each family as a case. Initially I tried to analyse the data from family interviews as a group; however, it became apparent almost immediately that doing so obscured the individual, sometimes divergent accounts. I therefore opted to draw out each individual voice from the interviews to elucidate their experiences.

The challenges of analysing QL data, and the lack of detailed guidance on how to approach such a dataset is daunting yet stimulating. As Smart (2010) notes, analysing and representing data sociologically '*becomes a creative act which is frankly terrifying*' (p.4). Henderson et al. (2012) suggest that the analytic style will vary with each analyst and that there is a need to remain flexible, imaginative, and to avoid a simplistic chronological description of the data. Ultimately I devised a four-stage analytic strategy:

Table 2: Analytic Strategy

Stage One (Completed after each interview)	Read and re-read the transcripts Condense data and tease out into individual perspectives Create a mind-map for each participant to identify categories of experience
Stage Two	Re-expand data into time-ordered matrices (Miles & Huberman, 1994) according to the categories of experience for all longitudinal participants. All the verbatim data is included in the time-ordered matrices to facilitate holistic re-engagement with the data set for each participant. Compare and contrast the categories of experience for each participant in a family, looking for relational themes.
Stage Three	Create individual longitudinal matrices (Saldaña, 2003) to delineate transitions and continuities over time, looking for motifs and through-lines (Saldaña, 2013)
Stage Four	Create a cross-case intergenerational matrix to bring the cases into conversation with each other

Examples of all four stages can be located in Appendices F, G, H and I.

The role of theory in data analysis

It can be argued that no qualitative research is atheoretical, since methodologies are themselves theoretically framed (McKenna, 1997). However, the extent to which theories are identified in qualitative research varies considerably, and theory is often poorly articulated, implicit, or retrospectively applied (Wu & Volker, 2009; Bradbury-Jones, Taylor & Herber, 2014).

In a qualitative longitudinal study the relationship between theory and data is iterative and complex; themes or concepts arising from early waves of interviews may prompt further reading of extant theory to elucidate the emerging phenomena, which in turn may influence data collection in subsequent waves. Analytic timeframes, often linear in other methodologies, tend to be less distinct in QL research; secondary analysis of data from earlier waves and primary analysis of later waves may occur simultaneously (Miller, 2015).

As McLeod (2003) and Gabb (2008) have noted, the nature of QL data can render it resistant to a single theoretical framework, and working within different, even divergent, conceptualisations can prove the most useful means of making sense of a complex data

set. This iterative logic has been described as abductive (Blaikie, 2007), in contrast to more linear inductive and deductive theory-research relationships. Moving back and forth between theory and data (Mills, 1959) can provide rich understandings of the lives of families experiencing young onset dementia.

Reflexivity

The positivistic view of researcher neutrality has been challenged by feminist qualitative researchers, who argue that researcher subjectivity is a resource rather than a form of bias (Olesen, 1994). Being conscious of one's own values and social location enables the researcher to critically examine the ways in which their agency influences the research process in its entirety, from the generation and refinement of research questions to the selection of the methodology, the data collection, and the analysis and interpretation of the findings.

However, as Jamieson et al. (2011) note, attaining a reflexive stance, while desirable in theory, can be problematic in practice, and may be influenced by one's status in academia. Having the confidence to write in the first person, for instance, can be challenging to early career researchers, and the candour required by a reflexive approach may be regarded with a degree of discomfort.

Nevertheless, it is my intention to briefly describe my location regarding dementia and personal relationships and my knowledge of the wider social context and to consider how these influences have shaped the study to date. Moreover, I concur with Neale et al.'s (2012) assertion that QL research touches the lives both of the researcher and the researched, and that therefore my location evolved as the study progressed.

At the beginning of Chapter One I described how an unconscious memory from my childhood emerged during the study, and how this unknowingly shaped the research. Knowing there has been dementia in my family is unnerving. Kitwood (1997) has written eloquently about how our collective fear of acquiring the condition is central to our social exclusion of people who have it; fear of frailty, fear of being dependent, but most of all, fear of erosion of the self causes us, in the defence of our own ontological security, to

reject those who appear to be losing theirs. Monitoring any defensive reactions of my own within interviews enabled me to critically analyse the process of data production within research encounters.

Moreover, working under the auspices of an institution founded on cognitive ability with people facing cognitive decline seems to me to exacerbate the power imbalance that already exists between researcher and researched. This assumption has shaped my endeavour to continually reflect on how people with young onset dementia might be empowered by the research process. Brief discussions following interviews have enabled me to gain insights into the process from the participants' perspectives, and attempts made to reinforce the sense of the participants being active contributors to the research rather than passive recipients of it are continually revised. In a similar vein, I have chosen not to label people with dementia in this study as 'sufferers' or 'victims' since I believe that such negative positioning detracts from their personhood (Sabat, Johnson, Swarbrick & Keady, 2011), a view that has been confirmed by The Dementia Engagement and Empowerment Project (DEEP) Language Guide (2014 <http://dementiavoices.org.uk/wp-content/uploads/2015/03/DEEP-Guide-Language.pdf>).

It may seem trite to suggest that a fascination with temporality intensifies as one progresses along one's own timeline, yet, my increasing interest in time and change has clearly influenced the focus of this study. The fluidity of meanings and interpretations and how they change over time is of great personal interest and has been a key factor guiding the choice of a longitudinal methodology. However, it is important to recognise that continuity, as well as change, is part of the human experience and that my analyses need to reflect enduring relationality as well as transition.

The wider political and social context has also shaped the way I have designed the research. Dementia has recently gained a much higher profile globally as numbers of people with the condition continue to rise and cures remain elusive. In the UK, two recent policy statements (Prime Minister's Challenge on Dementia, 2012; Prime Minister's Challenge on Dementia 2020, 2015) have emphasised the importance of developing strategies to enable people to live well with dementia, a value reflected in the mission statement of the recently-established Salford University Institute for Dementia.

Local Dementia Action Alliances have been established to drive forward the formation of dementia friendly communities, and the Dementia Friends scheme aims to increase public awareness and understanding of the experience of living with dementia.

Recognising the contribution people with dementia should make to developing services (Cantley, Woodhouse & Smith, 2005) influenced me to incorporate questions on perceptions of services into the data collection.

It is perhaps particularly important to reflect on the relationships with participants when engaged in a longitudinal study and how these may have shaped the data collection and analysis processes. While seeking to maintain a professional relationship with my participants, it is impossible when people are sharing such personal experiences not to develop some form of connection with them, and it is crucial not to neglect the effect of the research on participants' lives. On occasions, and particularly with Family Three, there was a sense that my presence was the catalyst for previously unspoken conversations to occur; indeed, within the family, one of the motivations for taking part, according to husband Ron, was to create a forum whereby Francine's sons could develop a better understanding of their mother's dementia. I have tried to indicate where I feel that my presence triggered a particular conversation, and have included excerpts of such dialogues for the reader.

I was continually impressed by the strength of spirit and the tenacity demonstrated by my participants who were trying to live the best way they could despite the presence of a terminal condition within the family. However, I also experienced sadness when faced with the decline in capabilities caused by the condition over time, and feelings of powerlessness when it seemed that there was nothing I could do to make the families' lives better. Clearly one makes choices when representing complex data, and I have continually sought to self-critique during this process, questioning the rationale underpinning the choices made about which data to include and which to leave out. At all times I have sought to capture the essence of the families' accounts, and to take the more difficult option of embracing and representing discordance rather than to create a unified but inaccurate portrayal of the participants' experiences.

In setting out the findings, I have opted to present each person's account individually, with the exception of Josie, whose account overlapped with other participants in Family One in such ways that it made more sense to intersperse her data with those of others rather than to present it separately. Despite looking at individual accounts, through the use of motifs and occasionally through-lines, I have sought to draw attention to intersubjective meaning-making processes as the participants interact with each other and describe their relationships with others.

Summary

This chapter has drawn on themes from the previous chapters to create a rationale for the choice of method for the study. Describing the congruence between the processual nature of symbolic interactionism and the temporality of QL research creates a cogent and robust framework for the study.

The design of the study has been described in detail, with due consideration to the research questions, the data sources, and data analysis. Ethical issues of conducting research with people with dementia, families, young people and children have also been discussed. The ethos underpinning the study, that of enabling the voices of marginalised groups to be heard and valued has been expressed, and attempts made to be reflexive have been documented. Attention will now be given to emerging findings, commencing with Family One.

Chapter Six : Family One

Table 3: Family One Participants

Generation	Participants	Waves of interviews			Family members not interviewed
		1 Apr 2014	2 Oct 2014	3 Apr 2015	
Generation where one person has young onset dementia	Louise, <i>living with Alzheimer's Disease</i>	✓	✓	✓	
	Jack, <i>her spouse</i> Interviewed together	✓	✓	✓	
	Josie, <i>her friend</i> Interviewed alone			✓	
Adult children					Jessica, Robbie
Grandchildren	Lauren, 12 years old Interviewed alone	✓	✓	✓	Leo, 11 years old Lucy, 7 years old

Louise

Context

Louise was 61 at the start of the data collection process, and had been diagnosed with Alzheimer's disease eight months prior to the commencement of the fieldwork. She has been married to Jack for many years and they have two adult children, Robbie, who lives 40 miles away, and Jessica, who lives locally. They have four grandchildren and two step grandchildren.

Louise has lived and worked in the same town all her adult life. She trained as a nurse in the 1970s and worked in various roles before her final employment as a nurse specialist in community nursing. She took early retirement from her position following the diagnosis.

Motif: Professional identity

Louise's pride in her professional identity is central to her sense of self and therefore to her experience of dementia. Professional identity formed a strong motif that persisted throughout the three waves of interviews; Louise expressed her connection to her past as a nurse frequently, both during the interviews, and by showing me two objects connected with her work, her old nursing bag, and a photograph album given to her on her retirement containing pictures of her and former colleagues. Her realisation of the emergence of dementia happened in the context of her nursing practice following the extension of the retirement age, and, indeed, she and Jack perceived that she would not have visited her GP if the symptoms had emerged after retirement:

***Jack:** Actually a few years ago when they moved the retirement age from 60 to 62 Lou went bananas, but in a roundabout way, in doing that, that has helped her to get diagnosed quicker, 'cause if she hadn't have been in work, and retired at 60...*

***Louise:** I'd have never have gone to the GP*

***Jack:** She'd had never have gone to the GP. She'd have said, 'I'm getting old, I'm getting forgetful' blah blah blah. But because it impacted on her work, because she was having to work an extra two years, this has fetched it up.*

***Louise:** If I'd hadn't been working and it hadn't been forced on to me in a way, I don't think I would've even gone to the GP* (Wave One)

Difficulties at work manifested themselves in a variety of ways which led Louise to question both her character and her professionalism. For instance, Louise reported throwing a book at a colleague who informed her she was repeating herself, and she described forgetting which type of medication she had given to a patient. For Louise, this behaviour was in stark contrast to her views of herself as a competent 'multi-tasker', a nurse who would be chosen to train others:

***Louise:** Girls who knew me... used to say 'who wants to know how to do the (specialist clinical technique) always go out with Louise, 'cause she never deviates from the way it's supposed... it goes ABCD, right to the end*

***Louise:** I was actually forgetting, you have a set routine...wash your hands, put your apron on, clean your trolley and I was getting to attaching the patient*

and...I hadn't flushed the line through. This was like, to me, this was a routine I practically could have done with me eyes closed... I got to the end and I thought 'God, I've not done half this whatsit' oh, I said, 'oh I don't know what's wrong with me tonight' passing it off (Wave One)

However, a turning point for Louise came when, during a confrontation with a patient's daughter, she struggled to complete important documentation. The daughter wanted to file a complaint because Louise had forgotten to administer medication to her mother, and when trying to complete the complaint form, Louise noted that:

Louise: *I can still remember my pen being on the paper. I remember that part of it. And I couldn't string... I couldn't write a sentence. It was all like, as if somebody had've got your brain and jumbled it all up. ..And I thought, I need to write something here, but, I couldn't put a sentence together... when I read it back it was the biggest load of crap you've ever... read in a legal document in all my life. It just didn't make sense at all* (Wave One)

Louise's colleagues gradually became aware of her difficulties. Another turning point in her experience was when several colleagues tried to help her remember which medication she had given to a patient by listing possibilities, leading one of her peers to jokingly ask 'have you got Alzheimer's or what?' and I said 'no I haven't, you cheeky git!' (Wave One).

Louise's awareness of loss of competence was further amplified by becoming lost and disorientated in the town she had lived in all her life. She frequently talked with pride of her awareness of local geography, of 'knowing all the short cuts' as a consequence of her role as a community nurse. While the concept of intimacy is often considered in relation to interpersonal relationships (Jamieson, 1998), or occasionally relationships with pets (Gabb, 2008), Louise seemed to have an intimate relationship with her locality, a strong and enduring sense of neighbourhood and place which was disrupted by her dementia. Getting lost in the town she has driven around for many years, then, is highly significant to Louise, and she reported it again in the context of her professional life:

Louise: *..Getting lost was one of the reasons that I knew there was a bit of something wrong 'cause normally I can fly around all ends of it... one night, the main one was a patient that I'd been to for ten years and got to practically the end of where I should have been and suddenly... even to this day I don't know where I ended up and the girl I was with, I said 'where am I?' and she said 'oh I thought you was taking me on one of your short cuts!' ... I don't know where*

I'd gone so she said well I'll get... 'turn left, turn right, turn this way' and we'd gone about, I'd say about 5 or 6 streets or whatever away (Wave Three)

The centrality of Louise's professional identity to her sense of self is further elucidated by the impact of having to give up work. While acknowledging the need to stop working because of patient safety, Louise noted that giving up work was '*like a bereavement*' and that at the time, it felt like the end of her life. However, by the third interview, Louise seemed to perceive a greater sense of separation between her professional identity and her sense of self:

Louise: *It's not like to me, oh it's the end of my life or anything like that, it's the end of my nursing life, but it's not the end of me (Wave Three)*

Using May's (2013) notion of 'belonging' as a conceptual lens, Louise's understanding of who she is is contingent upon to where and to whom she feels she belongs. Her sense of being a competent, trusted, knowledgeable and connected member of a nursing team and of the nursing profession formed a pivotal part of her sense of self, and her acceptance of the end of her nursing practice as a result of her dementia has had profound ramifications for her sense of belonging. She described losing long-standing work friends, and noted, with some resentment, that her manager, whom she had worked with for fifteen years, did not speak to her after her diagnosis, and communicated only by letter. Her diminished connection with her nursing workmates was highlighted in separate interviews both by her and by her former colleague and friend Josie, as the following two quotes illustrate:

Louise: *A lot of my friends were work friends... work colleagues as well... we were a big group of friends inside work and outside work, but a lot of that has stopped now. (Wave One)*

Josie: *She's still Louise, she's still the same person, and a lot of the people, friends, colleagues at work, they don't see her anymore... Like I said, I'd love to talk to them and say 'Why don't you come? Why don't you see her? She's still the same person, she's no different.' (Wave Three)*

However, although her sense of connectedness to former colleagues had diminished over time, Louise still clearly gained pleasure, and possibly a recaptured sense of normality, from talking about her nursing practice. She and Josie recounted various anecdotes to me with evident pleasure and humour, and among her remaining work colleague friendships, nursing still formed a substantial part of their conversations, as the following quote from Jack illustrates:

***Jack:** I mean her dear friend came the other night with her husband, and Geoffrey sat there and he's saying 'they're talking about work again, they've been retired two years, the pair of them' and I felt like saying to him 'Geoff, it's what they like to talk about'. I mean, Deirdre's not got it (dementia), but Lou loves it, she's 'Remember so-and-so? Oh, he was a right nasty old sod!'*

(Wave Three)

In a poignant quote, Jack emphasises the centrality of Louise's professional identity to her sense of self:

***Jack:** When the girls come from work, you can see her face lift, still, and she talks about work as if she's still there. The nurse'll never go out of her, you see, that'll be the last thing to go, that I think...the nurse*

(Wave Three)

Being part of the same profession potentially provides individuals with a firm foundation on which to form friendships (Spencer & Pahl, 2006). Recollecting shared memories in the present is an important means of sustaining friendships, and, as Smart (2007) has noted, individual memories are not formed and revisited in a vacuum; rather, memories are socially shaped, context-dependent and often suffused with emotion. Sharing memories of work is not only pleasurable for Louise, who has invested so much capital in her professional identity, but also for her friends, who have the opportunity to validate Louise through recalling shared memories of competence:

***Josie:** If Louise gets onto a topic, say the evening services, plus I feel that she can remember, she can remember back in the 70s, the early 70s... things that we did, and we have a laugh about that... but she was a fantastic nurse. She wouldn't leave a patient until she'd put 150% into that patient's care... I think reminiscing, it really helps her. Helps her to think she can remember*

(Wave Three)

Josie's friendship with Louise was also appreciated by Louise's granddaughter Lauren, despite the fact that she and Josie had not had a close relationship themselves. As Josie noted:

***Josie:** Lauren said 'I've never really liked you Josie' but she likes me now, she said 'you've been so good to my nana'. She never liked me 'cause I was always telling her, always saying 'you can't speak to your nana like that' but she likes me now, and we talk now, because she likes how I've been with her nana.*

(Wave Three)

Charmaz (1983) observed that friendships can fail in the context of chronic illness as ill individuals transition to different social worlds than their friends. Louise's experience of friendships in the context of dementia may support this theory. The loss of several of her work friendships may be because of the loss of a common social world; the friends that remain seek to re-establish their previously shared social worlds through recalling shared experiences.

In her study of family response to chronic illness, Gregory (2005) observed a tension between the reality of illness and the desirability of normality. One possible way of resolving this tension for Louise is in her use of the present to re-inhabit past events; at times perhaps preferring the competent active self from the past to the more constrained self of the present (Charmaz, 1991).

Motif: social experience of dementia

While Louise reported having lost friends following her diagnosis of dementia, she also created new social spaces. After initially attending support groups for older people with dementia, but feeling that they were not appropriate, she was informed by a dementia support worker that a group for younger people had been set up by a local charity:

***Louise:** She said, "are you interested?" And I said, "yes," because I didn't want to go with all the old people*

(Wave One)

Over the twelve month data collection period the young onset dementia support group played an increasingly important part in Louise's life, offering her support, a source of friendship, but also inspiring her to play a much more active role in raising awareness of

dementia. Louise became more involved in social and biomedical research, education, and consultation on community facilities for people with dementia. In the first interview, the purpose of the group seemed to be to offer friendship and support:

Louise: *'Cause she (another person living with dementia) can reflect the things that happen to me, and I can reflect the things that happen to her*
(Wave One)

However, in a later interview, Louise's through-line exhibited a greater sense of determination to be active; she had been joining other dementia groups and giving talks on her own personal experience of dementia:

Louise: *You can sit and feel sorry for yourself, or you can get out and do something about it*
(Wave Two)

This sense of agency is common among people with mental health issues, who, Orange (2011) argues, believe they will feel better if they can improve the conditions in which they find themselves. This also extends to improving the lives of others, as Louise drew an especial sense of satisfaction and pride at helping others with young onset dementia to join the group, especially those who seemed to struggle to incorporate the dementia into their sense of self:

Louise: *People who won't speak about it, who don't want to... who look on the blinkered and you know, 'nobody's gonna know that I've got dementia' and that. I brought another couple to the Dementia Champions group last week, who'd been on the DAPA (Dementia and Physical Activity) course...she enjoyed that but she didn't realise it was to do with a memory thing... she would never think of herself as having dementia or anything*
(Wave Three)

Louise's increasing sense of agency is likely to be connected to her greater sense of belonging to the social context of dementia, to her immersion (Charmaz, 1991; Baumgartner, 2007) in illness-centric activities. The growing public interest in dementia has led to more funding, creating opportunities for those with dementia to become more active and more involved in social life. Connectivity, for Louise, is key:

Louise: *I think keeping in contact with other people has helped me 'cause the first few weeks when I was diagnosed with it, it was like 'oh is this all you've*

got, you're going to be stuck in the house all the whole time nobody to talk to, nothing to do' 'cause obviously my life had been around my work before that, but now we go out to groups and clubs and as I say, we go to the Dementia Champions group so we're championing for change in all sorts

(Wave Three)

However, by the third interview, which occurred shortly after the general election, Louise expressed concern that future funding cuts may constrain the availability of services for people with dementia.

Motif: Constructing meanings of dementia

Even though Louise's father and grandmother had both had dementia, and, she felt, had probably developed it at a young age, she did not appear to have considered the possibility of developing the condition herself. As she wrote in her commentary 'My Journey':

***Louise:** 'I never thought this would happen to me as I was as fit as a butcher's dog, but it did and it could easily happen to any of you'*

(Excerpt from 'My Journey')

In terms of making meanings of the condition, then, Louise had seen good physical health as a preventative factor for dementia, and did not appear to consider the possible genetic link. Over the course of the fieldwork, Louise became increasingly physically active, going running with another person with young onset dementia and using an exercise bike at home. While Frazer, Oyebode & Cleary (2012) found that the sense of self of older women with dementia was affected by physical disintegration, for Louise, there was a sense of increasing fitness, which Lauren concurs with: *'my nana is fitter now than she's ever been'* (Wave Three). From the perspective of the embodied self (Kontos, 2004), Louise's desire to attain a high level of physical fitness perhaps nourishes her sense of self; seen physical improvements may in some way mitigate the unseen neurological degeneration.

Louise seemed to ascribe the occurrence of dementia to fate, and, with Jack, co-constructed the metaphor of a dealt hand of cards to symbolise this critical event in their lives:

Jack: *It's not what we expected our retirement to be, but we've been dealt this hand and we're playing it! (laughs) We're playing it the best we can!*

Louise: *We've got two aces and two kings and a queen instead of a royal flush!*
(Wave Three)

Buchholtz, Spiekermann, & Kächele (2015) have observed that metaphorical language is a form of abbreviation that creates rather than solely represents experience. The expression of this metaphor condenses yet could also be argued, creates Louise's experience. Louise's hand of cards, while not, as she indicates, the best hand in poker, is still a strong hand, and constructs a positive outlook on dementia. Louise noted that while initially she had '*put up barriers*', by the second interview she had '*come to terms*' with her dementia, through accepting its permanence and, using a phrase that has a high profile in modern policy discourse, '*living well*' with it. She also felt that she had progressed to a different level of incorporating her condition into her life as the following quote illustrates:

Louise: *It's not something I'm making up, it's something that's real to me, like it doesn't go away, how it happened, it doesn't go away, it's there, it's happened and I've moved on and that's what's happened really that I've moved on and I've come out the other side which, to me, I always do, don't I?*
(Wave Two)

Louise reported initially experiencing a sense of stigma, and a reluctance to tell people about her dementia. However, her attitude towards disclosure evolved:

Louise: *I think I felt that stigma when I first, I felt, don't tell anyone 'cause they'll only laugh at you and everything'll be 'oh don't tell her, she's got... she won't remember anyway' you know, big joke about it, and I think I was like that at first, but then 'cause I never told any neighbours or anything, 'cause I didn't want them... But, now I tell them, and if they don't like it, it's tough.*
(Wave Two)

This is an example of anticipated stigma (Chaudoir, Earnshaw & Andel, 2013), which describes the degree to which a person expects to be discriminated against or socially devalued by a characteristic. For Goffman (1963), the concealability of a trait was a key distinction in the experience of stigma. Whereas discredited people have an immediately visible difference, discreditable stigma relates to differentness that is not necessarily perceivable by others. People living with young onset dementia, particularly in the earlier

stages of the condition, are likely to experience discreditable stigma as dementia is socially constructed as an older person's condition, and behaviour associated with it would not be expected in a younger person (Chaston, 2011). Anticipated stigma can, therefore, be acutely experienced. When asked how people usually reacted to the disclosure, Louise noted that people usually reacted with surprise:

Louise: *Well actually the two that I told they couldn't believe it really, they were amazed, they said 'oh we just thought you'd' they thought I'd give up work because I'd retired*

Jack: *And then we met Sandra who I used to work with... and she said 'what you? you're not old enough!' there you go - that's the thing, not old enough to get it, she said 'yeah I've got it'. She was amazed, wasn't she?*

(Wave Two)

In making sense of her experience, Louise sought to construct a sense of normality through contrasting her behaviour with that of residents in her neighbourhood:

Louise: *(I don't) throw my rubbish out of the bin on to the floor. Them are people who are abnormal. When you live round here I think I'm more normal than the neighbours I've got! I am normal, very normal*

(Wave Two)

Dementia had also brought unexpected benefits. Louise described how, as a result of her dementia, she had lost a sense of fear and had also become more empowered, even emancipated, in social situations, as the following quotes illustrate:

Louise: *I'd do anything, me, I don't have a fear of anything now, I used to, I don't have a fear now 'cause I'm not used to being frightened of anything now*

(Wave Two)

Louise: *I lost a lot really, I had to give up a lot, but I've gained a lot. I've gained this... if people don't like what I say, tough. 'Cause I'm gonna say it anyway, you know, if they don't like it that's tough on them 'cause if it's upsetting me or it's worming its way in there, it's got to come out, so I just tell people now*

(Wave Two)

For Louise, a particularly meaningful example of this empowerment was her pride in changing the views of a senior nurse during a talk who felt that it was unnecessary for all nurses to know how to work with people with dementia:

***Louise:** This nurse who's a sister on this ward kept pooh poohing it and saying they don't need to know really, it doesn't really matter and then I spoke to them...she actually rung Mary (the event organiser) up and said, 'I'm sorry I'm ringing you at night' she said, 'but I couldn't get the woman out my head of how much it affected her and she's coped with it and how important it is that you listen and do the right thing'*

***Jack:** So that made Louise feel so proud, 'I'm useful, I'm doing something'*
(Wave Two)

Temporality

An important aspect of how Louise experiences dementia is the way she structures time. She describes routine as her '*saviour*' and talked about the importance of routine as a means of asserting control over day-to-day life in all three interviews, and perhaps a means of restoring a feeling of competence. For both her and Jack, their calendar was seen as a crucial part of their lives; it occupied a central space in the living room and they frequently referred to it and picked it up to show it to me during interviews, thereby emphasising its central role in their lives. For example, as Jack notes:

***Jack:** We've physically got to keep that calendar right next to us all the time, haven't we?*
(Wave Three)

Louise's daily routine involved applying her medication patch, eating breakfast and cleaning the house and doing the laundry before engaging in any activities planned for the day. Routines create predictability (Gregory, 2005), sustaining a sense of normality and ontological security (Giddens, 1991) through the repetition of family practices. The planned activities within the routine evolved over time; at the beginning of the fieldwork they revolved around either care of their grandchildren or attending dementia cafes, but as the fieldwork progressed there was a greater range of activities: engaging in research studies, awareness raising, acting as dementia consultants, educating people about dementia or campaigning for local change. For Louise, there was an increasing sense of immersion (Charmaz, 1991) in her dementia identity as the fieldwork progressed, however, interestingly, this is both a social and an individual identity; emerging perhaps

from the belonging and fellowship shared with other people living with dementia, as the following quote illustrates:

Louise: *We all seem to be getting on with life, we're not sitting thinking 'oh God this is the end for us sort of like we're going to end up like these who are not too good'. We don't look at it like that... in my job I've seen people who've got no capacity to do anything and people have shoved PEGs* in them and they've been lay in bed and all they've been doing is being fed by a tube and all they're doing is that all day and I think 'sorry, that's not my way of life' my life is getting up and going out and doing* (Wave Two)

*percutaneous endoscopic gastrostomy - a medical procedure involving insertion of a nutrition tube into a person's stomach when oral feeding is not possible

Keeping busy, and occupying time purposefully, became increasingly important to Louise over the course of the fieldwork. During the second interview, she revealed that their financial and medical plans had been formulated, including their Power of Attorney, wills, and funeral payments. She had donated her brain and spinal cord to medical research, creating, as Charmaz (1991) might suggest, a legacy through the perception of an 'everlasting' future (p. 255), and had discussed placing a Do Not Resuscitate request on her medical notes with her GP. For Louise and Jack, the presence of the dementia had created a sense of urgency, shifting their temporal focus and relocating the future in the present. As Louise notes:

Louise: *It stimulates you to get on and do, because you can sit back and say 'oh I'll do it tomorrow' like our wills and that, we've been doing our wills for 10 years and it's always been tomorrow, but then it become today...instead of thinking 'oh it'll never happen to me'...it makes you think you've got to get on and do what you've got to do, haven't you?* (Wave Two)

Future horizons

Although Louise's father and grandmother developed dementia, and she had played a significant role in their care, when she refers to her feelings about the future, she places it in the context of her professional, rather than personal identity:

Louise: *I'm here, and I know I'm gonna go there, and I don't know how long it's going to be, but I don't want to see the end result, 'cause I've seen that in my*

nursing and it's not very nice, and when you've seen it, you put it in the back of your head, in that bit where you've stored for out of the way stuff

(Wave One)

Louise prefers not to focus on the later stages of the condition, then, and views the future as something that cannot be controlled, and in the hands of fate. Worrying about her own deterioration in the context of this unpredictable condition seems to her to be futile; she has demarcated the areas of the future that she can control and has done so, as the following quote from the final interview describes:

***Louise:** I could be hit by a bus tomorrow...your life's planned out for you, whatever, you can't change...so why worry about what's gonna happen in the next ten, fifteen years, or in the next ten years or seven years or whatever, there's no use worrying about it, because you can't change it. I mean, you know, as long as everything's in place*

(Wave Three)

However, while Louise had chosen not to focus on the future, her close friend Josie found the prospect of Louise's decline very distressing. When I interviewed her, Josie was planning to move to Australia to be closer to her children. On a flight home from a recent visit, she had watched *Still Alice*, a film about a younger person with dementia, and stated that:

***Josie:** The tears were streaming down my face. I was heartbroken. And my husband said 'what's the matter?' and I said 'that's Louise, that's what Louise is going to be like'. What if we move to Australia and Jack can point the screen at her for Skyping, so she can see me - but what if he has to say to her 'that's Josie'? What if she doesn't remember who I am? Watching the film brought it home to me. I don't want to see her like that, like she is at the end.*

(Wave Three)

Thus, while Josie 'belongs' to the experience of Louise's dementia in the present, and in the near future, she anticipates that she will alter her relational practices with Louise as the condition progresses to the point where Louise no longer recognises her.

'Lost' time

Louise described her time between receiving the diagnosis, and receiving help and medication, as *'lost time'*, a time when she found it difficult to construct sentences and had frustrating experiences trying to access the services listed in a booklet given to her after diagnosis. Additionally, while she experienced some troublesome side effects of her medication, it helped her to recover her sense of self, although the time between being diagnosed and receiving medication was irretrievable:

***Louise:** You get angry because you've got this book with these names of people in, then you're told 'oh we know nothing about this, ring again in another month' sort of thing, but that's a month to me that was wasted because I needed to know now, not next month or the month after or the month after that...it was like three months later, four months later (before they got help), but that four months, to me was lost time of getting myself back to my normal*
[Jack: Medicated and normal, yeah] (Wave Two)

Following the medication, Louise felt more able to communicate and described herself as less irritable and frustrated. Over the course of the fieldwork she appeared to reach a point of greater acceptance of her word-finding problems, which she described as *'like a door closing'* in her mind. Accepting word loss, she notes that:

***Louise:** There are lots and lots of things now, it just doesn't come back and I just think to myself 'well, it's gone, why worry, whatever I was gonna tell you, it's gone.' And if it was important, then it's tough, that's 'cause it's gone, so that's how I feel now*
(Wave Three)

Independence

Although there were few apparent changes in Louise's capabilities over the course of the fieldwork, she did appear to experience a decreasing level of independence. She had stopped driving quite soon after her diagnosis, as she was struggling to maintain her concentration levels, and stated that she had to rely on Jack for transport, which she felt that he was sometimes reluctant to do. In the first interview she remarked that receiving a bus pass had given her a new sense of independence:

Louise: *I have now got a bus pass so if I do want to go out, to the (name of shopping centre), or to my daughter's, or to wherever on my own, I can, as long as I've got identification with me... But I can go, on the bus, I can go, I've got independence now, which for over twelve month I haven't had any independence... I can go to my friend's now. I've got independence again now, which I hadn't got, had I?* (Wave One)

However, by the third wave, Louise's sense of independence had diminished. She was losing her confidence to travel alone on the bus, and would only travel short distances alone and where her memory of place was intact. Thus a destabilising connection to place was impacting on her friendships:

Louise: *You lose your friends when you become, housebound, I would say housebound really 'cause whereas before I could jump in the car and go to them, I'm stuck unless Jack drives me I'm stuck in and the odd time I've been on a bus it has to be a place that I know well... I wouldn't catch a bus that I didn't know where I was going to, and I don't go far on the bus, only about a mile, about a mile at most I go* (Wave Three)

Effect on family relationships

Interestingly, Louise did not talk at length about the effect of her dementia on family members. Although the diagnosis had been disclosed to all of the family she assumed that younger grandchildren Leo and Lucy were too young to understand, and that while she perceived that eldest granddaughter Lauren understood the effects of dementia, that she was not deeply affected by it. She observed that her daughter Jessica was *'heartbroken'* after the original diagnosis, but felt that the improvement following her medication had to some extent assuaged her daughter's distress. However, she also reported that her daughter had declined to participate in the study because she would find it too upsetting.

Louise seemed to believe that Jack was primarily affected, and suggested that dementia might cause a break-up in some relationships. The following excerpt from the second interview demonstrates that sources of tension in the relationship arise from frustration and perceived risk:

Louise: *I do sometimes, get frustrated and I think probably he feels it the most 'cause he's nearest*

Jack: *She says things now it just goes over the top, I don't not a lot you can do about it, is there? I know she's frustrated.*

Louise: *Yeah he still gets angry with me, but I know he doesn't mean it, because it's probably me that's angered him, 'cause I've probably asked him the same thing 3 or 4 times or whatever [Jack: Or she does summat daft] or I do something completely dangerous, stupid or whatever*

Jack: *I do my best, but I'm only human like everybody else. I do my best.*

Louise: *I think he's good that he's still with me 'cause a lot of men wouldn't be*

Jack: *I don't know whether we want to go on holiday with our daughter and the kids and I think 'it's just too much for her, it's just too much for her' 'cause she'd blow up at the kids, not knowing what she's doing, it might be in a public place, she'd get embarrassed and all that you know what I mean, but, then again, you think well, if we get, if they get embarrassed, sod it, you know what I mean?*
(Wave Two)

Jack

During the first interview Jack was quite talkative, however the majority of his comments were reiterating or embellishing Louise's experiences; it was only during the second and third interviews that he spoke more openly about his own perspective. A possible reason for this initial reluctance emerged during the second interview with Lauren:

Lauren: *It's like he doesn't like attention 'cause he's like the head of the family, he doesn't like being looked after or he doesn't like the attention he just wants everyone else to be OK, he doesn't think about himself* (Wave Two)

In this context, Jack appeared to make several sacrifices to please other family members; sacrifices which, by the final interview, seemed to be becoming a strain. He talked frequently about how busy he and Louise were as a result of the dementia-related activities they were engaged in, the importance of their calendar to enable them to structure their time to manage their activities, and of how Louise would complete one research project only to enter immediately into another. The tempo of their lives seemed to have increased, and Louise's dependence on Jack for transport meant that he

perceived himself to be harried at times. However, engaging in the activities, he felt, provided a focus for Louise:

Jack: I think it's a motivation for Louise, it keeps her going, it really does, I mean sometimes it gets a bit of a bind. (Wave Three)

This was expressed more strongly by long-standing friend Josie, who, when discussing the possibility of Louise taking on a position of a part-time dementia ambassador role, demonstrated concern for Jack:

Josie: Now she's talking about this new job, but what with Jack running her around everywhere, and then they've got the grandkids...he's exhausted and she needs to realise that he's tired with it all 'cause he'd be the one having to take her... I like to give Jack a break. She doesn't realise, with all the things they do, like she'll say 'Monday we're here, Tuesday we're going here, Wednesday we're doing this' and she doesn't realise how exhausted Jack is

Motif: Managing effects on family interaction

Jack seemed to have a key role in trying to maintain a calm environment. He recognised that Louise's character had changed, and while stating that she had always been quick-tempered, felt that she was becoming more so, and was simultaneously less able to discern people's reactions to her:

Jack: It's changed her character. Definitely, definitely changed your character you're more ratty now and all... 'cause you think people are having a go at you and they're not. You get frustrated quicker, and that's why you're ratty. But as soon as you've done it, it's gone, it's forgotten (Wave Two)

He reported 'saying the wrong thing' at times, and 'hitting a nerve', and also described situations where he managed the behaviour of other family members in order to try and prevent tension. For instance, he reported telling his daughter to allow Louise to do her ironing even though Jessica didn't want her to do it, because it was becoming a sedimented, predictable part of her routine. Similarly, he told his granddaughter not to cause Louise to become irritated:

Jack: Lauren was here the other day and she was winding her (Louise) up something terrible so Jessica barked at her. She looked at me, I said 'just don't

wind her up', I said, 'you were getting her frustrated, you've got to learn not to do it'
(Wave Two)

Jack felt that as a result of the dementia he and Louise had become closer. He was determined to enable her to retain as much independence as possible, and was disparaging of family members he had met in dementia cafes who helped the person with dementia when he perceived the assistance to be unnecessary. In addition, he had developed various strategies to enable them to cope, such as creating and sustaining the routine and setting alarms on the cooker as a reminder to Louise. He also developed communication strategies, and noted how it was important to '*stay on the same plane*' as Louise to help her find words, and also to try and '*enter the world*' of the person with dementia. He contrasted this with how they had coped when looking after Louise's grandmother:

Jack: I just wish I'd have had the knowledge I've got now, and I could understand what was going through in her mind. But she was hard work though she was totally hard work. She used to sit there and say 'is that a pigeon up there?' 'no, it's a coping stone, Maggie'. 'Is that a pigeon up there?' 'no, it's a coping stone, Maggie'. 'Is that a pigeon up there?' 'no it's a coping stone' and we went on and in the end we should have said 'yeah it is a pigeon' that's what we should have said. We didn't realise...We thought she was winding us up, we weren't sure, were we?
(Wave One)

Developing his knowledge of dementia is one way Jack expresses his agency and helps Louise to live well with the condition. Certain aspects of the manifestation of the condition seem to be particularly difficult for Jack. For instance, Louise forgetting shared times together watching the television was raised twice in the interviews. The following quote is an example:

Jack: I said we watched that last night and she'll say 'I don't remember' so it's just things like that, you know, you think, oh God, she is... (pauses), you know what I mean, but anyway, then other things she can remember like that (clicks fingers) there's certain sparks that are there but a lot of them are not firing properly, you know, that's the nature of the disease unfortunately
(Wave Two)

Finding solitary space is one way Jack feels he deals with caring for Louise; he reported that he goes outside alone when he needs respite.

Making meaning of dementia

Like Louise, Jack construes the development of her dementia as '*bad luck*', rather than viewing it as potentially an inherited condition. He contrasts her increasing physical fitness with her mental difficulties and expresses a determined attitude towards the way dementia affects lives, and how he seeks to maintain some control:

***Jack:** This is it about dementia, you just cannot let it overpower you [**Louise:** Depress you] you've not got to let it depress you, that's one thing I've learnt, you've just got to, you've just got to go with it and learn to live with it*
(Wave Three)

For Jack, the invisibility of dementia is a salient feature of the condition. He and Louise regularly attend the local support group for younger people with dementia, and he mentioned on two or three occasions how difficult it is to tell who in the group has dementia and who is a family member:

***Jack:** Unless you get the ones that are really really bad and stand out like Shelley, you know if you ask her a question she can't remember her name and things like that, but most of the majority... 99.9% of them there you don't know who's the carer, you don't know who's the patient* (Wave Two)

The lack of distinction within the group between those with a diagnosis of dementia and those without may foster a sense of normality from Jack's perspective.

Motif: Humour

A recursive motif in the interviews with Jack was his use of humour as an essential coping mechanism. Humour formed a strong part of his relationship with Louise and he recounted how he teased her about spilling drinks '*she'll be* (spilling her tea down her top) *and I'll say 'how do you miss a gob like that'?*' or bumping into door frames '*it's been there for years the door, what's up with you?*'. In addition, the humour seemed to be a shared family practice. For instance, his daughter had created an acronym for forgetful moments:

***Jack:** That's what you've got to do, laugh. You have a damn good belly laugh about it all sometimes. You've got to. A CRAFT moment! Our Jessica come up with it - 'Can't Remember A Flipping Thing'! (laughter)...So that's another*

thing, we have, you see, it's laughter. Laughter's a great... I mean we were laughing at something at the club the other day and we were all roaring laughing, and I can't remember what it was, you saw everybody, every single person there was just in stitches and I thought 'what a great bit of medicine this is, you know'
(Wave Two)

From Jack's perspective this shared experience of humour within the support group seems to be a uniting experience, perhaps fostering a sense of belonging and shared identity within the group. In an earlier interview, Jack had recounted another experience that occurred within the family setting where group humour appeared to serve a similar purpose:

***Jack:** Medication's got you so that you can waffle and go on. Same as our kid says at Christmas that time, when we were all talking 'Louise, Louise, Louise' in the end he went up and touched her arm and said 'for Jesus' sake' he said 'them tablets are working, I can't get an edge in' (laughter) the whole place just collapsed, you know what I mean, so they're all in on it, you know what I mean, we've not held it back*
(Wave One)

Significance of the Support group

Over the course of the fieldwork the support group became an increasingly important part of Jack and Louise's lives. Jack spoke of camaraderie, a sense that everyone is '*in the same boat*', that it is a non-judgmental environment, and that the group share enjoyable activities. Attending the group seemed to give them a sense of belonging, cultivating the development of a social identity of young onset dementia. Lauren attended the group on one occasion, to donate funds that she had raised, which could arguably be a form of family display (Finch, 2007) in that they were conveying to the support group that they were facing young onset dementia as an intergenerational family.

Jack had experimented with attending carers' groups on his own. However, he had found them to be an unsatisfying experience:

***Jack:** I should go to these carers' meetings but I don't get anything from them, 'cause I don't regard myself as a carer, I'm her husband first, you see, so... and some of these carers' meetings, they get a bit heavy, and I think 'well I've come here to get away from it and you're all going about it' so I tend not to go to*

them at the moment. I only went to a few, and then we were supposed to be going out for a meal, and I think, 'What we going out celebrating a meal for, 'cause if I want to go out for a meal I want to go with Louise, not with strangers' you know, so it seemed to go against the grain for me, so I stopped doing that
(Wave Three)

The reason Jack did not feel supported by these groups, then, seems to be partly connected to his lack of desire to absorb a carer status into his identity, and partly because the function it performed was incongruous with his wish to sustain normality. He felt that people used the groups as a chance to complain about the person they were caring for, and that the group therefore created or sustained a divide between the couple rather than reinforcing the bond between them. He mentioned that at the young onset dementia support group, there was the opportunity sometimes for the carers to talk together, which was preferable:

Jack: Now, if someone wants to have a chat and a moan there, fair enough, they got some issues they want to bring up, something they want to get off their chest, well I can put up with that, but if you're having a carers' meeting to go out somewhere, you want to forget it, you want to talk about normal things
(Wave Three)

In some respects, relationships with members of the support group seemed to have replaced some of the previous friendships Louise had. For Jack, the group of former friends were 'selfish', who, he felt, wouldn't make the effort to visit, even though he and Louise had 'always made time' for them. He noted that Louise had made good friends at the support group, and that some of the friends had inspired her to become more active in campaigning for change. He too had become more active, not only in supporting Louise at various events, but also reported that he had become more inspired to get people 'on board'. For instance, he stated that:

Jack: If they get people like Asda, Morrisons, businesses on board so that they don't look at people, they see beyond the cover, if they start struggling they think 'yes, yes madam can I help you?' 'oh take your time, you're alright, don't worry, here y'are that's your money' and all that and that's what they want, you see, they want people to be aware of it because it's not got a sign. You've got dark glasses you're blind, but Alzheimer's, there's no (sign)
(Wave Two)

Future horizons

For Jack, the future held uncertainty in the context of Louise's dementia. However, he seemed to derive considerable peace of mind through eliminating anxiety with respect to those aspects of the future that could be controlled. Making advance financial and medical plans seemed to liberate the present for Jack in the context of uncertainty, as the following dialogue illustrates:

Jack: *I mean, we've not got a bucket list or anything like that but actually just sorting your finances out, because the nature of the disease unfortunately is, you don't know what's going to happen - very, very quickly.*

Louise: *Or it could be long*

Jack: *Or it could be long term but for the long term, you're not worried about, what happens if I have a heart attack, what happens if I lose capacity, and what're we going to do about money, or what happens if we both go, it's all sorted, the bills and everything, so, you can just get on with what you're going to do now, all the important things are done.* (Wave Two)

Additionally, Jack seemed to draw comfort from acting as a support to Louise's postmortem decisions, knowing that he would be respecting her wishes.

Louise: *All in line, that's on my medical records 'cause if I died, they've got the phone number for... to contact him, and then they will do whatever they have to do, you know, take the body, if I'm at the morgue, if I'm at the undertakers they take you from the undertakers to the hospital here and then take me back where I was but I'm not gonna know anyway 'cause I'm gonna be dead anyway, so*

Jack: *That's Louise's wishes and that's what she wants to do, so*

Louise: *That's perhaps 10, 15 years*

Jack: *Hopefully, yeah, you've got a fit body*

Louise: *I might have this bloody dreaded heart attack before then! (laughs)*

Jack: *You've got to, you've got to think positive haven't you?*

(Wave Two)

Lauren

Context

Louise and Jack's granddaughter Lauren was aged 12 at the beginning of the fieldwork and had her 13th birthday a few months before the final interview. Her brother, Leo, and her half-sister Lucy, were aged 11 and 7 respectively at the beginning of the data collection process. Lauren's biological father died in tragic circumstances when she and Leo were very young, and her mother has a partner, Phil, who is the father of Lauren's half-sister Lucy. Phil also has two children from a previous relationship, Deanne, the same age as Lauren, with whom she has a strained relationship, and Matt, aged 9.

Although the emotional impact of Lauren's father's death was not discussed by any of the participants, some reference was made to the effect on roles within the family; Louise and Jack, for instance, described how they had become much more involved with caring for their grandchildren to enable Lauren's mother Jessica to work. Lauren visited her grandparents' house frequently, remarked that she had '*always been close*' to them and listed shared activities such as shopping, walking and baking. She described her grandparents as '*like sergeant majors*' in their role of organising and looking after her and her siblings, transporting them, and cooking a meal every Sunday for all the family.

Motivation

It emerged in the final interview that Lauren's motivation for taking part in the research, and, indeed, in other dementia-related activities, was to please her grandmother, however, in the final wave she reported having enjoyed participating in the research and felt there was a clear purpose in her doing so:

Lauren: *When my nana first asked me a year ago, I just said 'yeah OK' 'cause my nana asked me to do it so I said 'yeah'. But then I found it interesting to talk about it... you've learnt things as well because it's like people don't know about dementia as in... I mean, I know people do know about dementia and a lot about Alzheimer's and everything but they don't know the day to day, like how people deal with it and stuff like that, so I think it's good to tell people about that*
(Wave Three)

Interestingly, her degree of candour was negotiated with her grandparents prior to the first interview:

Lauren: *When we knew you were coming today, we talked about that for a bit, and I was like, 'will you be all right?, shall I just say what I feel, or shall I try and protect?'*
(Wave One)

Lauren's behaviour during interviews suggested that she was open about her feelings. Interviews took place in the living room, and, while her grandparents initially left the room, they would often need to re-enter it to answer the phone or to walk through to go upstairs. Every time one of them entered Lauren would stop talking and I would move the conversation to a more anodyne topic. As they exited the room, she would look over her shoulder to check they had left before continuing with the original subject.

Construction of Family

When asked to describe who was in her family, Lauren included Phil, Deanne and Matt in her list of family members; however, she rarely referred to them during interviews and principally mentioned her mother, grandparents, Leo and Lucy in the context of Louise's young onset dementia. Other family members, such as aunties, uncles and cousins, were occasionally referred to, although it seemed that the people she classed as her immediate family had a different experience of Louise's dementia. This is encapsulated in the following statement:

Lauren: *The tiniest thing sometimes can make her go on a massive rage about nothing, but she's never really done anything in front of the family before, like had a thingy, like it's only really me, my brother, my sister, my granddad and my mum that see it*
(Wave Three)

This could be interpreted in various ways. For instance, Louise may only feel comfortable displaying this perceived emotional volatility in front of her closest family. She may fear judgement or a stigmatising response from other family members. Using Finch's (2007) concept of family displays, it could be argued that Louise's emotional expressiveness could be a means of conveying to Lauren and the others in the group that these people belong to the 'family-experiencing-dementia'; relationships predicated on commitment,

connectedness, acceptance and tolerance within which the effects of the dementia can be safely expressed without fear of opprobrium.

However, referring to the family as a singularity obscures the complexity of the differences between them in terms of how they relate to Louise's dementia. For Lauren, it is apparent that her mother Jessica experiences the manifestation of the condition in a different way to her:

Lauren: *Every time my mum sees her, she's like, 'she's getting worse, you can tell she's getting worse', but my mum hardly... Because she's always working, she doesn't see her a lot, whereas I see her all the time so I can't see as big a change as my mum, but my mum says that every time she sees her, like when we're on the car on the way home, she's like 'you can tell she's changing, can't you?' and I'm like, I can't tell that much every time I see her that there's anything different* (Wave One)

Similarly, according to Lauren, Leo and Lucy have a less intimate experience of Louise's dementia. Lauren perceives that her sister is too young to have a comprehensive awareness of the condition, stating that:

Lauren: *She doesn't understand like what it is if you know what I mean, she just thinks Nana's got a bad memory* (Wave Three)

Although she perceived that Leo had a better understanding, she felt that he was, to some extent, indifferent towards it:

Lauren: *I don't even think Leo knows how to become a Dementia Friend, or what a Dementia Friend even is* (Wave One)

Lauren: *He doesn't like take any interest into the actual disease, like he doesn't really bother with it* (Wave Three)

Lauren viewed her grandfather as having the most awareness of Louise's dementia, and described the nature of his actions as conciliatory, trying to mollify her grandmother following an emotional outburst. His focus, from Lauren's perspective, was to try to 'make sure we're all OK'. She seemed to view her own role as one in which she supported her grandfather by giving him some respite. She was very conscious of the strain experienced by her grandfather, as the following quote illustrates:

Lauren: He's getting quite stressed...say he comes to our house, and we were, like, fighting, and he'd spent all day with my nan, repeating things and snapping at him, so, he'd get quite tired (Wave One)

Lauren appeared to view herself in the role as the main supporter for her grandfather and substitute carer for her grandmother. When he was briefly hospitalised she went to stay with her grandmother to help with her medication and to ensure she was eating regular meals.

Therefore, although from Lauren's standpoint, the experience of the dementia might be more closely shared with this group, rather than with the wider family, the ways in which members of the group respond to it differ quite substantially. She felt that, of the group of children, she had been affected to the greatest degree, and the two key facets of Lauren's perspective of how she had responded to her grandmother's dementia are captured in the notions of 'being there' and 'knowing about dementia'.

Motifs : 'Being There' and 'Knowing about Dementia'

The most salient motifs in Lauren's interviews were the concept of 'being there' for her grandparents and the importance of 'knowing about dementia'. These notions pervaded all three interviews, and were closely entwined for Lauren; being co-present with her grandparents, but trying to understand how her grandmother might be experiencing the dementia during that shared time, and therefore how she might best support her, were central and recurrent concerns. There was also a moral undertone to her descriptions of these central themes, a suggestion that this is what people should do when someone in their family has dementia. In seeking to delineate and express her own social action, she contrasts her behaviour with that of her younger brother:

Lauren: I don't think Leo will seriously understand how serious ... the disease is, and what the potential... And I think he will have some regrets when, maybe if she does get worse, that he wasn't here, and spending as much time with my nana, when she was able, and able to be herself (Wave One)

Towards the end of the data collection period, Lauren's perception of her brother's involvement changed. During the first two interviews, Lauren noted that, instead of spending time with his grandparents, Leo usually went to play with friends or went upstairs to use the playstation; however, by Wave Three, she reported that he was beginning to share the responsibility of supporting their grandparents; moreover, that between them they were administering the space in the house as a strategy to defuse tension and offer support. Thus she and her brother had intersubjectively created meaning about their grandmother's dementia, and were taking action on the basis of the meanings made:

***Lauren:** He's getting closer to my granddad, like he spends more time with my granddad making sure he's OK and stuff whereas I spend time with Nana making sure Nana's OK ...so Leo'll go off to my granddad into the kitchen but I'll just stay in here with my nana to make sure my nana's OK ... but like I think it's good that if Leo goes to Granddad I can go to Nana so my nana's not left out and my granddad's not left out*
(Wave Three)

This notion of spatial administration also seemed pertinent to Lauren as an individual. For her, 'being there' comprised two key elements: maintaining her relationship with her grandmother, and supporting her grandfather through creating the opportunity for him to have respite, as the following quotes illustrate:

***Lauren:** I try to see my nana as much as I can, in case she does get worse, and then I don't, like, have a connection with her anymore... And my granddad, as well. 'Cause my granddad gets (stressed)... so, sometimes he just goes up and sits in his room, so I just give him his space and if my nana, say, I can just sit down here with my nana instead of her bugging my granddad constantly. So, be there for my granddad as well*
(Wave One)

***Lauren:** 'Cause of my nana's illness, I know she's not gonna be around forever so I like to spend as much time with them as possible, and my granddad, 'cause like he gets stressed out and that upsets me when I think of him when I'm not here so I like to spend time with him*
(Wave Three)

According to Lauren, sharing time and space with her grandmother reduced her awareness of changes caused by the dementia. For example, she remarked that both her uncle and her mother noticed more differences because more time elapsed between their contact with her:

Lauren: My mum notices it every time she comes she goes, 'your nana, your nana's getting worse' or 'have you noticed that about your nana?' but I don't notice it 'cause I see her like practically every day (Wave Three)

However, she also noted during the same interview that:

Lauren: You learn things about the disease every day with my nana, like new things which she does that are different to usual (Wave Three)

While discordant accounts are common in qualitative research interviews (Power, 2004), these apparently contradictory statements may, on closer inspection, be less contrary than they appear. As previously mentioned, the notion of 'knowing about dementia' is the second key recurrent motif. 'Learning' about dementia is a slightly different construction to 'noticing' changes; while the latter implies observation and comparison with an earlier schema, the former is indicative of ongoing knowledge construction, a process which permeates Lauren's experience.

Motif: 'Knowing about dementia'

The other prominent recurring theme in the interviews with Lauren was the importance of developing knowledge about dementia. Although this process did not commence at the point of disclosure - Lauren reported having previously seen a character with dementia portrayed on *Coronation Street* - she felt that her limited awareness had a negative effect on her response when she received the news. Describing her experience of the disclosure of the diagnosis during Wave One, she talked about initially '*thinking it was a joke*' and '*laughing*'; she reported only becoming distressed when she became aware of other family members' sorrow. Hochschild's (1998) notion of the '*collectively shared emotional dictionary*' (p. 6), a repository of cultural emotional response, is drawn upon by individuals in the context of social interaction. In this instance, Lauren judged herself to have initially displayed an inappropriate emotional response and she subsequently drew on the emotions displayed by the adult family members in order to create a shared family practice.

She expanded on her initial reaction during the third interview, when she alluded to a sense of regret about her behaviour. This regret was clearly connected to her lack of knowledge about the condition:

Lauren: *When I found out about my nana's dementia I wish I wouldn't have been as careless, like I would have been more bothered but I wasn't because I didn't know what it was* (Wave Three)

Lauren actively sought information about dementia, and often demonstrated her knowledge during interviews. For example, in the first interview Lauren described how she had been on the Dementia Friends course and how being informed helped her to develop her understanding of the condition. Discovering the condition was terminal proved to be a shock, however, and was not something that had been communicated within the family:

Lauren: *I didn't know it was terminal, I didn't know it was a terminal disease...my granddad knew, my nana knew, and I went 'what, terminal? That means you're gonna die?' and they was like 'yeah, did you not know that?'* (Wave Three)

Towards the end of the final interview I asked Lauren whether there was a message she would give to another young person in her situation. Her response explicates the connection between the two motifs of 'being there' and 'knowing about dementia':

Lauren: *Be there for your relative but also make sure, before you're there for them, make sure that you know what it actually is, 'cause ...I've grew closer to my nana because of the dementia but when I first found out she had dementia I didn't really take any notice of it, like you just, you don't think it's anything, you just say 'oh right' like I didn't, like when we found out my mum and granddad were dead upset but we were just like 'oh it's dementia' if you know what I mean, because you don't actually know what it is* (Wave Three)

Lauren also discussed the limits of her knowledge, and the extent to which she could empathise with her grandparents, and in doing so, highlighted the difference between knowing and experiencing:

Lauren: *No-one actually knows how my nana's feeling with the dementia, what she remembers, what she doesn't, what she feels about like the diagnosis* (Wave Two)

Lauren: *'Cause like I understand the disease and everything but I don't understand from my granddad's perspective* (Wave Three)

For Lauren, her grandparents' membership of the local young onset dementia group represented an important forum for them and provided a function that family members were unable to:

Lauren: *It's a chance for them to have fun but with people who understand what they're actually going through* (Wave Three)

Imaginary family and social life: future horizons

Lauren frequently framed her statements regarding the future in a conditional way; for example, she used phrases such as *'if she gets worse'*. Lauren's awareness that dementia is a progressive condition is without doubt, therefore her use of a conditional mode of speaking is suggestive of an occasional reluctance to accept the reality of the dementia. This is evident in her statement during the second interview:

Lauren: *If my nana ever forgets something it's like I don't want that to happen. I just want her to stay as she is now instead of forgetting anything* (Wave Two)

However, Lauren also spoke of the need to use the present to create pleasant memories for the future, so that her Granddad would be able to remember Louise as *'happy not sad'*. Similarly she noted that their family holiday in May 2015 *'might be the last one Nana can choose to go on'* and possibly the final holiday that they would share as a family.

Lauren was conscious of the need to make the holiday enjoyable for Louise, and had hopes that the shared family time would be more pleasurable than usual. Her imagined holiday demonstrates an idealised view of family life rather than the day-to-day reality:

Lauren: *We meet up for Sunday dinner, but something always goes wrong, and someone gets in a mood, or someone's not happy, but when we're on holiday I think it'll be different* (Wave Three)

Imagined futures that Lauren constructed extended to incorporate people beyond her immediate family. For example, she expressed a hope that members of the public would

help her grandmother if she had difficulties in a shop queue, and noted that while people can be rude, they:

***Lauren:** Need to think what if it was their mum or dad, or what if they were in that situation they wouldn't want everyone to be just tutting, they'd want someone to help them... just help them 'cause they were getting distressed*
(Wave Two)

Public constructions of dementia

However, Lauren perceived the lack of visibility of dementia can be a problem for the general public:

***Lauren:** You wouldn't think of it as a terminal illness, like people wouldn't see that when they look at my nana, like when you've got chemotherapy you lose your hair, so people would know but you can't tell with my nana 'cause she's so normal you wouldn't guess*
(Wave Three)

Lauren expressed a certain frustration with the lack of knowledge about dementia within the general public. She perceived that people obtain their information about dementia from television programmes which might be misleading due to the variability of the condition:

***Lauren:** It's not all like 'oh yeah if you get dementia you're going to be like this' 'if you get Alzheimer's you're going to be like this' 'cause you don't know, you don't know what to expect, so people think like when they've seen it on telly or something 'they're not gonna remember me or they're not gonna be like this' because that's the character that was played on the telly*
(Wave Three)

She felt that people should know more about dementia, and expressed disappointment that the topic had not been addressed in school:

***Lauren:** I think it should be in schools more, because if my nana didn't get dementia I still wouldn't know anything about it now, because there's nothing in my school, nothing like, no workshops in school, nothing that actually tells you about it, no charity events, no stuff like that. I think it's important that people do know about it because they might get someone in the family that does get dementia and they won't know what to do like I didn't know what to do, and I do think that that's hard because you don't understand*
(Wave Three)

Interactional disruption

One of Lauren's most challenging experiences was dealing with the interactional disruption caused by her grandmother's memory loss. This was a common theme across all the interviews, although it appeared to be becoming a more intense and distressing experience by the third wave.

During the first interview, Lauren noted how she found it difficult that Louise sometimes could not participate in recounting shared memories, the retelling of stories that is often central to our experience of family life (Thompson, 2005; Smart, 2007). In some instances, this was something relatively quotidian, for example:

***Lauren:** She's forgetting about... things that happened last week, and me and granddad would be here just having a giggle about it, and my nana would just be there, like, 'what are you laughing at?' and that would upset me, that she'd not remember at all*
(Wave One)

To Lauren, then, her grandmother's lack of ability to remember shared experiences proved distressing. Remembering and recounting shared events intersubjectively is a deeply meaningful aspect of family practices (Morgan, 2011), and to be unable to interact in this way unsettles the processes by which family relationships are reconstituted, and the way the self is formed and reformed through interaction with others (Mead, 1934). Knowing there is a reason for the memory loss may ameliorate, but does not eliminate, the distress caused by the inability to collectively revisit shared experiences.

A poignant example of this process occurred when Lauren became upset as a result of her grandmother's inability to remember a significant family event:

***Lauren:** When we buried our nan's (Lauren's great-grandmother's/ Louise's mum's) ashes, it was on a Mother's Day, so on Mother's Day we went to see my nan's grave, and I was like 'oh yeah, it was two years today that we scattered her ashes here' and my nana was like 'no, it wasn't on Mother's Day, it wasn't on Mother's Day' and she'd forgotten when we actually buried her mum's ashes, and was getting really stressed because she thought she was right, so, that got me upset because I was close to my nana Anna as well... so that she forgot upset me*
(Wave One)

According to Gillis (1996), commemorating the dead in cemeteries fulfils an important place in the modern construction of family, providing a seemingly permanent space for families to symbolically recreate a sense of themselves in an insecure world. For Lauren, this experience could potentially have a disassembling effect on her symbolic construction of family, perhaps compounded by the cultural significance of Mother's Day as a day to honour maternal figures.

Forgetting past shared family events, then, was experienced as distressing by Lauren in the earlier interviews. However, by the third interview, the interactional disruption seemed to have become more located in the present moment rather than being connected to something that happened in the past. Lauren, while noting that her grandmother '*had always been shouty*', began to talk about her grandmother's '*massive rants*' or '*massive rages*' that were triggered by '*the tiniest thing*'. However, from Lauren's perspective, Louise would appear to quickly forget the argument:

Lauren: *Yesterday we were just having a normal conversation then she just went on a massive rant and I was like 'nana, calm down' but she wouldn't listen then she walked upstairs then came downstairs and wanted to try my shoes on! After she'd just shouted at me for doing nothing, then she just wanted to try my shoes on!* (Wave Three)

The unpredictability of conversations with her grandmother, and the perceived need to suppress her own emotions in response to her grandmother's outbursts, led to a sense of frustration for Lauren. As she notes:

Lauren: *We just have to know not to like bite back at her when she's going mad over something that's not big...so you're not making it worse. If you know you're right, and she's ... my nana's wrong, you can't say that that's what's happened, you've just got to like go with what she's saying* (Wave Two)

Both Lauren and her granddad use the strategy of '*walking away*' when Louise becomes emotionally volatile. Entering another space was only one of the strategies used; others included not interrupting her when she was talking, and trying to guess words that she struggled to recall.

From Lauren's perspective, elements of her grandmother's personality had become more extreme; she felt that Louise was both more tense and also more sociable and humorous. Indeed, Lauren felt that she was becoming more alike in personality to her granddad:

Lauren: *She'll go and sit with my mum while she's working she'll just chat away, whereas she used to be really anti-social ...apart from when she's like really stressed she's nicer to be around* (Wave Two)

Lauren: *She wouldn't really socialise with people, but now she does, she's come more like my granddad as well, talkative* (Wave Three)

Transgenerationality

As well as becoming more like her granddad, Lauren also perceived that her grandmother had changed to become more like someone of her own generation. This theme arose in the first interview but was expanded upon in subsequent interviews. While initially, Lauren noted that her grandmother had started to buy more fashionable clothes '*she wears like, sparkly jeggings*' (Wave One), in the two later interviews she noted that she had become more interested in beauty treatments, and also that her sense of humour had changed:

Lauren: *She's going back to childhood... because sometimes it's like speaking to my nana, 'cause I speak to her in confidence with stuff, but then it's like we have a giggle about things that you wouldn't normally giggle to your nana about* (Wave Two)

Lauren: *My mum's baffled 'cause she wants facials doing... but like she never used to... 'cause my mum was doing me a facial and my nana's like 'I want one! Why've you not asked me for one?' so ... she wants it because I'm having it* (Wave Two)

In the final interview Lauren perceived that Louise had to some extent repositioned herself in the younger generation:

Lauren: *She's more young, like she wants to do things that everyone else is doing, like with the iPad, we was in the shop the other day she was like 'I'm gonna get another iPad, I'm gonna get the newest iPad', and I said 'what are you gonna do with the old one' 'oh I'm just gonna keep that one for games'...*

and she's got a Facebook account (Louise enters to find a pen then leaves) it's like then, she was creeping around laughing and giggling, she would never used to, she would just walk through stomping through to get it, she would never make a joke out of creeping (Wave Three)

According to Giddens (1991), an individual's sense of identity is underpinned by the crucial connection between language and memory, enabling people to develop an autobiography that is both rooted in and shaped by differentiation between time horizons. Biographical continuity, he argues, is central to one's sense of ontological security. Arguably, therefore, memory impairments could undermine an individual's ontological security, increasing the permeability of the self. Extrapolating this argument, it could be postulated that a less stable self may be more pervious to the influence of others, and that, in the context of dementia, the boundaries between the self and other (Holdsworth & Morgan, 2007) may become more precarious.

Family communication about dementia

Lauren noted that communication about dementia between family members did not occur on a regular basis, rather it was usually only in response to a particular event. Lauren reported that her mother Jessica, who spent less time with Louise, often asked Lauren to confirm or deny changes in her.

Jessica's frankness about her concerns did not appear to be typical within the family, rather, there was a sense of protecting each other from the effects of the condition. Lauren noted, for example, that Louise was reluctant to tell anyone when she was feeling low, and that her granddad sought to protect the grandchildren from the effects of Louise's dementia.

Similarly, Louise's dementia was not discussed in the wider family, as Lauren notes:

***Lauren:** Like all of my other family they don't mention it to my nana or anyone, like my aunties and uncles, my nana and granddad's brothers and sisters, they don't mention it 'cause it's not ... at the end of the day, they're still a person, they're still the same person just not as they used to be, but it's like when we meet up with relatives we've not seen in ages they know about my nana's disease but they won't just go 'oh how's your dementia?'* (Wave Three)

This suggests that the family practice around Louise's dementia is to focus on principally on her personhood rather than her pathology, supporting rather than diminishing her identity (Sabat et al., 2011).

While Lauren noted that family members would joke about certain events that occurred because of the dementia, for example the time Louise bought cat food thinking it was tinned tuna, there was little affective communication within the family. For Lauren, this was due to a fear of causing distress to others within the family. This desire to protect family members, however, could lead to a sense of isolation. In the first interview Lauren stated that:

***Lauren:** I hate speaking to my mum about things, so...my friends at school are the only people I would... Because I'd never talk to my nana about it, 'cause she'd probably get upset, and, my granddad would, so I just speak to my friends, because they've not (got dementia) in their family... So they probably won't get upset if I'm talking about my nana, so I just go to my friends instead of my family*

(Wave One)

***Lauren:** As long as it's in my mind I don't need to mention it to them or anyone else but my granddad does sometimes mention to us like 'you need to be good for your nana' or 'you need to make sure you help your nana' like when we stay, or 'don't like mess around'*

(Wave Three)

During the same interview however, Lauren noted that in actuality she rarely talked to her friends about her grandmother's condition, and suggested that she would only talk to them if a particular event had distressed her. In general she considered her peers to have different priorities to herself:

***Lauren:** But some people – some of my friends have totally different lives, like one of my friends is ...like, really rich and everything, so they're more about the money and not the family, whereas we're not the richest people ever, so we've only got each other*

(Wave One)

***Lauren:** 'Cause they're always like there, I'd rather have my nana and granddad than Twitter, but they just post everything on Twitter, broadcast it to the world*

(Wave Two)

As well as feeling a sense of disconnection from her peers in the context of her grandmother's dementia, she expressed a reluctance to inform and receive support from her school. She viewed her grandmother's condition as '*not the school's business*' and, moreover, tended to disapprove of people who she perceived used family difficulties as a reason to be late with homework. Comparing the stoic response of friend Molly whose grandfather had died to a peer who she felt was using a bereavement as an excuse, she stated that:

***Lauren:** Molly just went on, tried her best, whereas Becca, she never hands her homework in to this day, and she says 'oh, my grandad died a couple of months ago, and my mum can't find the time' like, when she forgot her P.E. kit, 'to put the wash on,' whereas Molly gets really annoyed when she does that, so I just do what Molly does, just keep myself to myself* (Wave One)

This statement gives an insight into how Lauren socially constructs meaning around family illness or death and support. Her peers' attitudes and behaviour clearly shape how she has developed a sense of what is a publically acceptable response to family difficulties. Lauren's disinclination to inform the school of her situation, while potentially depriving her of a source of support, is consistent with the meaning she has constructed about the self-reliance grandchildren should develop in response to a grandparent's illness or death.

Over the course of the fieldwork, however, Lauren's construction of self-reliance appeared to evolve. Reluctant or unable to speak to her family, her friends, or her school in the first two interviews, Lauren effectively had no arena, other than the research interviews, to discuss her feelings. However by the third interview, she noted that she had created new friendships, relationships in which, due to a common experience of grandparent illness, there was space to safely share her thoughts and feelings, even if her friends, from her perspective, did not know about dementia, as the following quote illustrates:

***Lauren:** I've got new friends since then, and my friends now...they listen, they listen to me more, they take more notice, but like my friends now, one of my other friends, her granddad's... can't walk, my other friends' nana's got cancer, so we all like listen to each other if you know what I mean like we don't say 'oh dementia's not as bad as like other things' like we just, we all just like take the time to listen... like my nana has been nasty in the past but they went 'oh is*

that your nana's dementia?' and I went 'yeah I'm so sorry' they went 'it's alright', like my new friends are more thingy but they don't understand what it actually is
(Wave Three)

It is interesting to reflect on the processes by which Lauren's social action creates spaces to discuss the effects of her grandmother's dementia. For instance, she deemed her participation in the research gave me the opportunity to learn about day-to-day life with dementia. She feels able to talk to her new friends because they share a common experience of ill grandparents, yet perceives that they do not understand the nature of the condition. Therefore she creates spaces to discuss the dementia with people who do not directly or indirectly experience the condition, and chooses not, or only very rarely, to discuss it with those who do. Locating conversations about how Louise's dementia affects her beyond the boundaries of 'family' suggests that there may be a perceived lack of legitimacy at expressing her emotions in the context of family relationships.

Activism

While family conversations about the affective response to Louise's dementia were rare, it would be inaccurate to state that there were no discussions or activities at all about Louise's dementia. Over the course of the twelve months' data collection process Lauren became more actively involved in dementia-related activities. For instance, apart from attending the Dementia Friends training, and participating in the research, she joined in the memory walk with her mother, and, in addition, raised £50 for the local young onset dementia support group by making and selling loom bands to her mother's clients. She was also starting to bake and sell cakes to raise further funds, and she attended a meeting of the support group to deliver the money and to receive a thank you card.

The money she raised contributed to a trip to Blackpool for the members of the group, which gave her a sense of personal satisfaction:

***Lauren:** They had a really nice time seeing the lights and everything and with the last time they've got they need to enjoy it ...while she can remember it and while she's with it they need to make good memories like not just for nana but for my granddad 'cause my nana won't remember them but it's my granddad that will*
(Wave Two)

She also participated in a YouTube video to educate others about living with young onset dementia. Becoming immersed in a condition has been discussed with the chronic illness literature (Charmaz, 1991; Baumgartner, 2007) although in the context of the person diagnosed with the condition rather than a relative. In a state of 'immersion', a transition has occurred whereby the condition occupies a central position in the individual's identity. Arguably, Lauren's increasing participation in fund-raising and educational activities denotes a sense of immersion, whereby the meaning she endows the dementia with is shaped by a sense of purpose and agency. In general, Lauren's sense of agency in the context of her grandmother's dementia is substantial and enduring; all three interviews are punctuated by the word 'making', often in the context of '*making sure*' a relative is 'OK' or '*making good memories*'. Interestingly, the space occupied by Louise's dementia in the practices of this family, from Lauren's perspective, seems to be less in the affective and more in the pragmatic domain; feelings are rarely discussed, but practical activities are undertaken to ameliorate the effects of the dementia on the family, and, more broadly, to try to improve the lives of people living with the condition.

Summary

Sabat et al. (2011) have drawn attention to the crucial ways in which a person with dementia's sense of self is affected by those with whom they interact. Those who focus on the pathological label diminish the humanity of the person with dementia, whereas those who focus on the person rather than the disease create the opportunity to support the person's self-worth and agency. Within this family and friendship group, Jack, Josie and Lauren undertook various activities to support Louise. Josie drew on their mutual nursing and friendship history to bolster Louise's sense of self through creating a shared space whereby she could revisit her professional identity, while Jack and Lauren supported Louise to become more immersed in her developing identity as a person living well with dementia.

In terms of family practices, with the possible exception of Jessica, there appeared to be a strong desire to protect each other from the effects of Louise's dementia. Practices seemed to occur more in the pragmatic than the affective domain of family life; spaces

were actively created to ameliorate the effects of interactional disruption, and to support Louise to develop her activism, but direct communication about how individuals within the family group were emotionally affected seemed to be rare. From a temporal perspective, while Josie talked quite openly about her fears for Louise's decline, members of the family seemed to focus on only those aspects of the future that were subject to control, such as advance medical and financial planning. The present, liberated by the controllable future, was managed through creating structures of routine, with an increasing focus on occupying time with dementia-related activities. Creating predictability within the context of a condition with an unpredictable trajectory may serve to construct a renewed sense of ontological security.

There was a focus on maintaining Louise's independence through offering help only when it was needed; in this sense family practices were constructed that aimed to protect Louise's sense of agency and feelings of self-worth, and moreover to share pride in her ability to make changes to the attitudes of health care professionals and to the lives of other people with young onset dementia. Humour, particularly in the form of 'CRAFT moments', formed another facet of family practices as family members sought to use humour to relieve the tensions created by memory loss and interactional disruption.

Louise's friendships had undoubtedly been affected by her diagnosis, with many former work friends appearing to avoid making contact, perhaps viewing Louise principally in terms of her condition rather than her personhood. Within her remaining, valued friendships, and new friendships that were developing within the context of a social identity of dementia, Louise found a source of support to both draw comfort from revisiting her former professional identity and to construct a new identity as a dementia activist. While changes in Louise's self were perceived by Jack and Lauren, notably with the sense of a relocation to Lauren's generation, there is less a sense of diminishing self and more of an evolving one, fostered in part by the broader socio-political context; the increasing public profile of dementia has generated opportunities for people living with dementia to campaign for change, to belong to a social dementia identity, and in doing so, has created spaces for empowered, agentic selves to develop. Family and friendship practices which enable rather than constrain the reconstitution of self have an important role to play in supporting people to live well with dementia.

Chapter Seven : Family Two

Table 4: Family Two Participants

Generation	Participants	Waves of interviews			Family members/ friends not interviewed
		1	2	3	
		Sep 2014	Mar 2015	Sep 2015	
Parents of person with young onset dementia					Violet Jonathan
Generation where one person has young onset dementia	<i>Julia, living with Posterior Cortical Atrophy</i>	✓	✓	✓	Phillip (brother) Sophie (sister-in- law)
	Peter, her spouse Interviewed together	✓	✓	✓	Colin and Celeste <i>(friends)</i>
Adult children	<i>Eliza, daughter</i> Interviewed with Julia and Peter			✓	Naomi
Grandchildren					Joshua, 12 years old Shannon, 9 years old

Julia

Julia was diagnosed with posterior cortical atrophy (PCA) in 2011 at the age of 56, a rare form of Alzheimer's disease that impairs both cognitive capabilities and vision, leading to blindness and advanced dementia.

Julia is married to Peter and they live with dog Freddie. They have two adult daughters, Eliza aged 42, and Naomi, 39. Naomi has two children, Joshua, 12, and Shannon, 9. Julia's parents, Violet and Jonathan, are 87 and 88 respectively. All family members live in the local area.

Motif: 'Entering a different world': constructions of normality and difference

For Julia, the experience of her PCA gave her a sense of separation from, as she termed it, 'the real world'. In particular, this feeling of being beyond the bounds of normality seemed to be triggered by events that caused a diminution of her sense of agency, for instance, creating a Power of Attorney. Relinquishing responsibilities to her family members was initially undermining to her sense of personhood, as illustrated by the following quote, which exemplifies a sense of not belonging:

Julia: When we did the thing with the girls [Peter: Power of Attorney] I was a bit down in the dumps about that as well, and I said 'but you're taking everything away from me'...that made me quite miserable as well, I was a little bit miserable for a couple of days then because I thought 'I'm not really a person anymore' do you know what I mean, I'm here, but I'm not really doing anything
(Wave One)

Another example of Julia's perception of occupying a different space was her retirement from work as a result of her PCA. Julia had always taken a great sense of pride from being a working person; she described her job as a shop assistant in a small local shop as pleasurable, and her employer, upon learning of her PCA, made efforts to minimise her responsibilities to enable her to continue working. However, her moral sense of identity as a working person was strongly associated with notions of competence, and she experienced guilt at earning money that she perceived to be undeserved:

Julia: I felt guilty, you know what I mean, and I just was getting so wound up about it, wound up about the fact that I couldn't, I couldn't do my job like I used to be able to do my job, you know, and I liked working in that little shop, 'cause it was quite a happy shop to work in... I think when I left work that's when I really did feel down in the dumps didn't I, 'cause that's confirmed, that, you know, you're not gonna be in the real world again
(Wave One)

Driving was another activity that Julia had previously enjoyed and had constructed as an aspect of normal existence and a part of her sense of self. Indeed, it was her sudden experience of confusion in the car that caused her to suspect that there was something wrong:

Julia: So I went to get in the car, and I just didn't know what to do, I absolutely... it was like getting into a spacecraft, you know what I mean? And Peter said to me 'what's wrong with you?' and I said 'I don't know what to do' I didn't know which... anything to move or anything and so he sort of got a bit 'oh what're you talking about?' you know 'you gone mad?', and that was it, that was sort of like the first thing, that was a shock. And 'cause I used to love, absolutely love, driving (Wave One)

These turning points in her experience of PCA served to create a distance between her and her construction of a normal life. During the year of the fieldwork Julia observed that her dementia had progressed, and as it did so, this sense of detachment from a normal life appeared to increase, as elder daughter Eliza confirmed during the final interview:

Eliza: Well, you say you're going into a different world, that's what you say (Wave Three)

During the same interview, Julia constructed her sense of self as positioned somewhere between normality and insanity, as the following quote demonstrates:

Julia: I know I'm not normal, but I don't feel like I've got... I don't have any traits of madness or anything, it's not a madness (Wave Three)

However, her attendance at support group meetings, which increased as the fieldwork progressed, seemed to provide an opportunity to develop a new sense of normality with other people living with young onset dementia. She describes one of the social events in the following way:

Julia: It's actually walking along and talking about everything and talking about each other and talking about our families and, you know, it's just like normal people meeting up (Wave Two)

Experience of Diagnosis

A key aspect of Julia's experience of PCA is her path to diagnosis. Since PCA typically presents as a visual problem, diagnosis of this form of dementia can be protracted (Crutch, Lehmann, Warrington, Warren & Rohrer, 2012), and, in Julia's case, she attended appointments for eighteen months at the eye hospital before the underlying pathology was discovered. Believing the condition was related to her vision rather than her brain,

the diagnosis was inordinately shocking for Julia. Unfortunately, the insensitive manner of the delivery of the diagnosis added to her distress:

Julia: The specialist... he literally come in the door, sat down, and he said 'well we know what you've got now' and I said 'oh good, maybe you'll be able to put it right' and he just literally really coldly and everything said, he said 'well you've got dementia and you will be blind' and I was on my own and I just I couldn't believe it, and he said 'erm, do you want your husband in, or if he's here or anything'... I just cried all the way back because it was just such a shock. I didn't expect, I honestly didn't expect that, I just expected that it was something really weird with my eyes but not that it was that. I wouldn't have even given it a thought
(Wave One)

Julia's embodied construction of her eyes being the source of her difficulties clearly impacted upon her experience of the diagnosis and shapes her perception of how the diagnostic experience could be improved for other people with PCA:

Julia: It just turned out that you know, my eyes, you could take them out now and put them into your head if you wanted, 'cause my eyes are perfect, it's just the brain. So I knew then that there was no hope, and that was it really...I said to him (her dementia care consultant) 'you really need to get the eye people to know about this PCA, the way it comes through the eyes' the eye route, rather than going to the brain bit. I mean it doesn't make any difference in my case because I've got it and that was the end of it, but you know, it would be nice for other people who wouldn't have to go to the eye hospital for over a year
(original emphasis)
(Wave One)

Julia's instant reaction to her diagnosis was to externalise the disease, calling it '*the shit*', an objectification which, although its use lessened slightly over the course of the fieldwork, formed an ongoing part of her and her family's practice with respect to her PCA. Her dementia care consultant validated this externalising practice by opting to use the term himself during appointments.

Bad days: Temporal and spatial management

Julia's experience of her PCA is punctuated by '*bad days*', when she struggles to think, speak, or get dressed. In response to a bad day, she creates an isolated space for herself; in her words, '*I just shut meself down*'. Julia usually either goes to bed or spends time

sitting quietly and listening to the radio. She constructs her experience in an embodied way, using vivid imagery to portray an external object affecting her internal cerebral functions and restricting her capability to engage in her day to day life:

***Julia:** It's just a rubbish day, that's what I call a rubbish day, it literally is... it's like as if you take your very good brain that you've got, and take it off, and then put a lump of concrete on top of it, you know what I mean, and I can't do anything... I have trouble even putting a pair of pants on or something, it's not because of the eyesight, but it's just that it's my head, I just come in here, and I put the radio on, and that's where I'll stay and I, you know, I can talk for England, but I can't on those days*
(Wave Two)

Entering an individual space and becoming absorbed in the music while the bad day passes, then, is Julia's way of managing the periods of time where she is most affected by her PCA. Family members facilitate her solitude; Peter usually performs household tasks and elder daughter Eliza offers to telephone the following day:

***Eliza:** I just go with the flow... if I phone up and Mum's having a bad day and Dad says 'oh she's been in bed since three o'clock', 'well, does she want to talk?' 'No she doesn't.' 'Well I'll call tomorrow'*
(Wave Three)

According to Julia, her parents Violet and Jonathan had recently offered to look after her in their house during a bad day, a suggestion which she felt was insensitive to her preferences, and, furthermore, was a tacit criticism of Peter's care of her:

***Julia:** She (Violet) phoned yesterday for something and I was really bad yesterday, I had a bad day yesterday, and I said to her, 'cause I do tell her now when I'm... and she says 'how are you our Julia?' and then I tell her, I just give her the list that I'm having that day, and she says 'well why don't you come down to our house?' Like as if Peter's not looking after me! And I said 'no, Mother, I'm staying at home I don't want to go anywhere, only stay at home'*
(Wave Two)

Throughout the year of the fieldwork, Julia's annoyance at the experience of bad days seemed to give way to a form of acceptance, combined with a belief that stress would worsen the experience:

***Julia:** I know how to deal with them, I'm not really bothered with them, they're not, particularly painful, it's just that I ... I just can't even think, let alone talk*

about anything. I mean, if I, if I got stressed, it's gonna get worse, that's the way I look at it
(Wave Three)

Motif: Being a daughter with PCA

The connection between stress and her intense experiences of her PCA was most clearly exemplified by her relationship with her parents. Indeed, Julia's description of her relationship with her parents Violet and Jonathan formed a strong and highly significant strand of her experience of her dementia. Having always had a troubled relationship with her mother, who she described as a '*hard, hard person*' Julia noted that her childhood was one of material provision but little affection:

Julia: We always had, the best clothes, the best shoes, but there was not much loving there, do you know what I mean? I'd have rather not had all the frocks
(Wave Three)

Julia felt that her mother's priority was to construct a social portrayal of the family as wealthy and successful, throwing expensive birthday parties for her and her brother when they were children, but not to demonstrate physical affection or encourage emotional closeness within the interior world of the family. Because of the existing strain in their relationship, Julia delayed disclosing her diagnosis to them. While her daughters were told straight after diagnosis, and her friends and acquaintances were gradually informed within six months, it was two years post-diagnosis before she felt able to tell her parents. Smart (2011, p.549) has described the '*subtle choreography*' of the management of secrets within families, a complex process underpinned by micro-social power dynamics through which some family members are included and others excluded from knowledge. Predicting that her parents would view the condition as a shameful occurrence within the family, which would be incongruent with the successful image they wished to display, Julia agonised about if, when and how she would inform them. Eventually, the effort of maintaining the silence, combined with the fear that they might hear the news from a mutual acquaintance, started to take its toll on her health, as the following quote illustrates:

Julia: I couldn't ...I couldn't even find the words to tell them 'cause they're both in their late 80s...but then it was making me ill...my mother... she just don't

believe it, she just thinks it my eyes. I said 'it's not my eyes there's nothing wrong with my eyes, Mother' I said 'it's my brain' 'oh well I don't know about that'. She just don't accept it... and then of course she was a bit annoyed because they weren't told when everybody else was, but I just couldn't say it to them. I thought 'how am I going to tell my mother and father at that age that I've got dementia?' and it was very hard anyway because it was making me ill... literally every night I'd go to bed and I'd try and find the words to tell them without shocking them and of course because people knew, we were worried that somebody would walk around in the centre there and say 'shame about your Julia, isn't it?'
(Wave One)

Having made the decision to tell her parents, the process of disclosing her PCA was very distressing for Julia, and her mother's immediate reaction was disappointing for both her and Peter. Instead of demonstrating sympathy, Violet reportedly chose to consider how Julia's PCA might impact upon her own future care:

Julia: *So I just said to her 'well I've got, it's called, well, you'd have heard of it, and it's a dementia' and I was umming and ahing I couldn't get the word out, do you know what I mean, I just didn't want to say it, it was so hard, just to say the word!*

Peter: *And then she (Violet) turned round to Jonathan and said 'oh my God' she said, what're we gonna do now, we're relying on Peter and Julia to look after us! [Julia: That's the first thing she...] Not 'oh sorry about that'*
(Wave One)

In general her father was perceived to be more accepting of her condition. However, Julia noted that he became tense when she attempted to embrace him *'as if he's gonna catch it!'* (Wave Two) and that he also implied a disapproval of her claiming welfare benefits, an attitude which angered Julia:

Julia: *(He said) 'there's too much of that going on, getting all this money from the' [Peter: Government]. Oh I was so mad! And I said to my dad, 'don't you think that I would rather be getting up at 7 o'clock in the morning, all weathers, going into the shop that's always goddamn cold? I'd rather be doing that, than have this, and then having this money. I'd rather go without'*
(Wave One)

There were further conflictual elements in Julia's relationship with her mother. One aspect of this is her mother's perceived embarrassment at the potential social response to

the condition. Julia perceived her mother to be deeply ashamed of her dementia, and predicted that she would 'veer' her away from acquaintances that they might meet in the town centre. Additionally she perceived that Violet is indignant that she and Jonathan were the last to learn of the condition. From Julia's account it can be suggested that Violet is experiencing associative stigma (Catthoor et al., 2015), a form of stigma generated through a significant relationship with a stigmatised person. This experience, Catthoor et al. (2015) suggest, may be particularly acute in parents as a consequence of a belief that they are in some way responsible for the child's condition. Indeed, Julia had suggested to her parents that her dementia may be genetic, which could potentially intensify their experience of associative stigma:

***Julia:** I said to them, 'well it's all about the genes, it's not my fault, it's the genes' and they argued between themselves!*

***Eliza:** 'It's not me!'*

***Julia:** 'It's not me!' (laughter). Then again, my (maternal) grandmother had it*

(Wave Three)

Violet's memories of her own mother experiencing dementia may be a significant element of her reluctance to accept that her daughter also had been diagnosed with a dementia condition. According to Julia, Violet had always denied that her mother had dementia. The secrecy Violet attempted to construct around her mother's condition was largely ineffective, however, as Julia and her brother were old enough to be aware that their grandmother's behaviour was socially inappropriate, even if they did not know the cause. The complexity of the intergenerational experience of dementia is further compounded by Julia and Peter's suspicions that Violet herself may be in the early stages of dementia:

***Julia:** My mother said she (maternal grandmother) didn't (have dementia) but the reason she was running around in the nuddy and in a home and she was asking to go home every day, I mean we were children but we weren't, looking back, we weren't stupid, you know... and my mother is a bit... she's not far off really, and because of the things she does, and the things that I do, and she does, I think she's.... you can't say that they have a bit of it, but she's definitely got something, do you know what I mean, because she sort of like does things. And I have said to my Dad, I said, 'is Mum alright?' I said 'she's nearly as bad as me' (laughs) and he just pooh-poohs it, he's just like 'there's nothing wrong*

with her' but now he follows her round in the kitchen, and stuff like that
(Wave One)

The intergenerational experience of dementia has unsurprisingly raised concerns for Julia about heritability for her own children. She noted in the second interview '*hopefully it doesn't go down the girl route, seeing as we got two*' (Wave Two).

Julia also expressed frustration about her mother's apparent lack of interest in either reading the information Peter has provided about PCA, or in the support groups that she and Peter attend. Moreover, when I arrived for the final interview, Julia said '*I feel very let down*'. When I asked why, she remarked that she had invited her parents to attend the interview, and while they had initially shown interest, they had withdrawn on the day with what she, Peter and Eliza all perceived to be an excuse. Her disappointment was particularly acute because in the context of her PCA, it was, as Peter declared, '*(the) first time you've ever asked them to do anything for you, isn't it?*'

Finch and Mason (1993) argued that individuals within families and kinship networks acquire reputations that are constructed on moral grounds, in other words, the manner in which they behave towards other family members. Within this family, Julia's parents, and particularly her mother, have demonstrated to Julia a denial both of her and her grandmother's dementia and a consequent lack of support and interest, a criticism of her acceptance of welfare, and a sense of shame at the effect of the dementia on the family's social standing. Their moral reputation is further impoverished by her perception of her mother's jealousy of their close friends Celeste and Colin:

***Julia:** She don't even rate them because they're so good to us, so it's like a jealousy, and she can't even bring herself to call my friend (by) her name*

(Wave Two)

For Julia's parents, then, dementia appears to be a source of shame, most appropriately managed as a family secret. That others beyond the boundary of 'family' not only know about the dementia but are actively engaged in helping Julia and Peter, is reportedly perceived by Violet as an inappropriate form of relational and social practice.

Julia, Peter, Eliza and Julia's brother Phillip all constructed and maintained Violet and Jonathan's moral reputation. Julia reported that her brother, on hearing of her parents' reaction to the disclosure of her diagnosis, remarked that her response was predictable:

***Julia:** If you knew my mother [**Peter:** You'd know what we mean] and I told my brother what she said, and he turned round and he said 'well, what would you expect her to say?'*
(Wave One)

Over the course of the fieldwork, Julia appeared to become resigned to the nature of the relationship with her parents and began to withdraw from contact with them. Inspired by listening to a radio interview with Dolly Parton, who stated that she avoided the company of people she perceived to be negative, Julia decided to restrict the amount of time spent with her mother and father. Visits to her parents often made her feel stressed and miserable, and, she felt, triggered her '*bad days*'. By the third interview, she reported that her visits to her parents' house were very rare, and that she would leave immediately if they said anything that caused upset to either her or Peter. Interestingly, this created some tension with Peter, who, while feeling angry with her parents because of their treatment of both him and Julia, felt that they had a moral obligation to visit regularly, and was concerned with social perceptions of their reduced visits. Thus negotiating the '*morally appropriate course of action*' (Mason, 2008, p. 36) in the case of Julia's parents was difficult, and there was a divergence between Peter's and Julia's perspectives, with Julia perceiving obligation to visit parents as belonging to a different historical moment:

***Peter:** If I had my way I'd never go in the house*

***Julia:** But I keep telling you I don't need to go down there*

***Peter:** That's the thing it's what people think, and it is your Mum and Dad at the end of the day*

***Julia:** What people? Yeah, but that's old-fashioned.*

***Peter:** We've got to do it for that reason, haven't we?*

***Julia:** But if people treat me badly, I don't know whether it's because of what I've got, I just, I don't have any of this now, I just look after myself now.*

(Wave Three)

Motif: Interfamilial disclosure experiences

Julia's troubled relationship with her parents caused her the most distress within the family while other relationships appeared to be characterised by commitment and love. However, there was relational tension regarding the disclosure of her PCA to family members. Peter, Eliza and Naomi all told other people without consulting her in advance, denying her the power to control the flow of knowledge about her condition. Julia expressed annoyance that Peter had told Naomi about the diagnosis immediately:

Julia: I wouldn't have told them straight away, just like that, but because they knew I'd gone to the hospital again - eyes - Naomi phoned him up, and Peter said 'oh well it's not very good news'. I said to him 'for God's sake!' I probably swore at him 'what did you tell her for?' And he said 'well, I don't know, it just come out' so probably it was 'cause he was in shock and and then of course we had to tell Eliza... the first thing she did, because I said to her 'I don't want you telling anybody, not because I'm ashamed of it or anything like that, I just don't want Nannie and Grandpy getting hold of it' and what did she do? She went and told her relations, her in-laws and they are a huge family and I was absolutely gutted, I had such a row with her over that, and I said, 'look, the one thing...' she said 'Mum, I couldn't' she said 'I couldn't cope with it, I had to tell somebody' so she thought it was better telling the other side

(Wave One)

Perhaps recalling her parents' unsuccessful attempt to maintain secrecy of her grandmother's dementia, Julia opted to download a leaflet designed to inform children about dementia. She gave it to Naomi, with the aim of discussing with her how and when to disclose her diagnosis to her two grandchildren, Joshua and Shannon. However, the children, aged 10 and 7 at the time, were informed by Naomi without asking Julia first. According to Julia, Naomi became aware that Joshua had noticed her and her husband 'whispering' about Julia, supporting Morgan's (2011) assertion that children and young people can employ a 'gaze' (p. 93) within family settings to observe and generate understandings of the behaviour of adult family members, particularly when there are specific family concerns.

Julia found Joshua's reaction to the disclosure of her condition very upsetting. Although Naomi didn't describe the later stages of the condition to him, his pre-existing knowledge

of Alzheimer's disease meant that he knew that his grandmother would be likely to forget who he was in the future. This awareness had a profound effect both on him and on Julia:

Julia: He had his hoodie on, and Naomi explained it to me, she said 'Mother' she said 'he was going further and further down into the settee' in their house, and he was like this (mimes hoodie pulled up around face) and the head was looking down, and he just popped his little eyes and he'd been crying, he'd been weeping, 'cause he knew what it meant, when she said Alzheimer's, he said 'oh I know what that is' 'cause the kids know everything now don't they? And he sort of like popped his little head up and he said 'but Mummy I don't want Nannie to forget me' (sighs). It's the first time I've said that without having a little weep
(Wave One)

Following the disclosure, Julia reported that '*no more's been said*' to the grandchildren. Her relationships with them seemed to transition over the course of the fieldwork, which they understood as related to the children's developmental stage and their increasing independence and expanding social worlds; Shannon, who had, at the beginning of the fieldwork, helped her grandmother considerably '*she's running round me like a little slave*' (Wave One) seemed to be becoming a more distant figure by the third interview '*she don't come up very often, she's 10 now, she's got all her mates*' (Wave Three). Julia perceived Shannon's knowledge about her condition to be minimal: '*it went over her head, I don't think she even knows about it*' (Wave Two); however, Shannon's behaviour suggests that she at least understands Julia's problems with vision. During the first interview Julia commented that she and Shannon would go out walking with the dog where Shannon would help her to cross the road and would point out tree stumps or other obstacles in the path. Additionally, during the second interview Julia noted that:

Julia: If she knows I'm going to get something, she'll be over there and she'll have got it before I could say boo, she's very good. She's like a little nurse really but she likes doing it and I don't want to alienate her by saying 'oh no, Nannie can keep on doing it'
(Wave Two)

Shannon's reduced involvement has coincided with the visual and cognitive decline that occurred for Julia between Wave Two and Wave Three. The family did not describe a connection between the two processes, perceiving Shannon's fewer visits as related to her social development:

Julia: They have so many mates where they live, it's really nice, and they've got loads of friends and everything so I think (the visits are) just when she feels like it (Wave Three)

In contrast, Julia's relationship with grandson Joshua, which she described in terms of embodied affection rather than conversation, seemed to become closer:

Julia: I used to go up and give him a big hug, and that then went down to a little kiss and a hug, then it goes down to sort of like a bit of a hug, and now it's like I'll say 'alright, Joshua?' and he'll say 'yup' (laughs) (Wave One)

Julia: He'll look at me and he'll give me this great big smile, but he still don't talk to me, but he knows what I've got and he's getting better now. If I go up to him, instead of him going like that (mimes cringing action) like they do, the boys, he'll give me a hug and stuff, so that's as good as I'll get, which is great (Wave Three)

It is apparent then that Julia does not expect practical help from her grandchildren, but accepts it when it is offered. She clearly wishes to retain an emotional and embodied affectionate connection with them. Her PCA is not discussed with her grandchildren, and she assumes that her grandchildren have differing levels of awareness of it. Joshua is the same age as Lauren from Family One, and while direct comparisons are inadvisable, Lauren had clearly constructed a sophisticated knowledge of the condition and was able to articulate in detail how her grandmother's dementia affected her and her family. She was reluctant to discuss it with her family for fear of upsetting them, and it is possible that Joshua, who had reportedly observed secretive conversations between his parents about Julia's dementia at the age of 10, and who already knew that family members can be forgotten as dementia progresses, also lacks the space to discuss the dementia within the family. An increasing inclination to express his love for Julia in an embodied way through looks, smiles and physical affection may be demonstrative of his reluctance to verbalise his feelings about Julia's PCA but his desire to maintain the connection between them.

Embodied connectivity

The embodied connectivity described with Joshua was also evident in the relationship with her brother Phillip, who Julia described as a loving yet taciturn man. For both of

these family members, connecting through smiles, embraces, or tears seemed to be a preferred communicative practice to discussing Julia's PCA. Julia is aware through Phillip's embodied communication that he is distressed by her condition, and perceives that it is his wife's - rather than her or Peter's - role to comfort him. She also notes that he has offered to share time and space with her, and has constructed his moral reputation in the context of her PCA in the following way:

***Julia:** I know he loves me, and I love him, but he don't see too much of us, and when I do go down there, it's because his wife asked us to come up... she's really lovely and she's the best person I know really, apart from Celeste and Colin...But every time, when I do go up there, and I go over to Phillip to give him a hug before I go away, and he, he [**Peter:** Tears in his eyes] cries straight away, so I don't think he's coping really but you know, Sophie (his wife) is there. You know, there's nothing I can do for Phillip really, because I said to him 'you can come up to me Phillip whenever you like' but he said 'no Julia, you know I like to be in my own home' he said, 'you can come every single day, even if you just want to sit there and look out in the garden', so that's... he's done the offer (laughs). He knows what it is, so... it doesn't bother me, you see, because it's not... I know he's sort of like hurting really but, you know, there's nothing I can do for him, I mean, Sophie is there, she knows all about everything, they might talk about it between them, I don't know.*

(Wave Two)

Temporality

Julia experiences an altered sense of temporality, commenting that time no longer concerns her. Peter appears to have become the custodian of Julia's time, as evidenced in the quote below:

***Julia:** If we have to go out somewhere I know he does it, but I don't say it to him, but he'll tell me about half an hour or an hour [**Peter:** 'cause I know it takes her longer] for me to get ready, otherwise I'll froust around... Or you'll say 'we're running late now, we're gonna be late!' and it's like 'oh for God's sake!' and it just doesn't bother me. I know I have to get there, I'm aware that I have to go somewhere, but ... I don't care what time... what day it is*

(Wave Two)

She expressed the view that she had had to adhere strictly to clock time in her roles as a mother and as an employee and felt that it was no longer necessary for her to do so; furthermore, her PCA had affected her notions of time to the extent that it was necessary for Peter to manage her time for her:

Julia: Peter is very structured, but then he has to be really, doesn't he?... Every time we've got somewhere to go, I'd say to him, 'go to that calendar and put it on' ... in fact we're more busier than we were before I had it

(Wave Two)

Over the course of the fieldwork, Julia and Peter seemed to experience an increasing sense of busyness. At the start of the data collection process, they perceived that there were a lot of opportunities to connect with others with dementia but only occasionally attended the local young onset dementia support group: *'there is, to be quite honest with you, you could be doing something every day if you wanted to... but we've got a big garden and we're always pottering about and doing something outside'* (Peter, Wave One) but by the second interview they were also attending PCA-specific support groups, and by the third were diversifying into other activities such as giving talks and participating in a questions and answers session after a local showing of the film *Still Alice*. This immersion in dementia-related activities increasingly structured their everyday life, as, over the period of the fieldwork, Julia withdrew from other social groups such as the local Irish Club, where they had been committee members for many years.

The present seemed to develop a greater intensity for Julia as she considered how best to use her remaining time. Aware that people with PCA are expected to live only around ten years after the onset of symptoms, she and Peter decided to take more holidays; they went to Europe and Scotland in the final months of the fieldwork, and had also planned a future coach trip abroad, to a country where they had spent many happy family holidays. During the final interview, Eliza and Julia talked with great enthusiasm about the previous holidays they had had, recounting shared memories of enjoyable times. However, this was tinged with sadness as Eliza compared the adventurous nature of their previous trips to the scheduling of the planned holiday:

Eliza: We used to go (there) all the time, like we used to have proper adventures, we'd literally get in the car and we wouldn't know where we were

sleeping that night, just literally get in the car and go...but this is all organised, so we know where we're going, we've got itineraries' (Wave Three)

The ability to be spontaneous, then, has been arrested by Julia's PCA, and previous family practices relating to time and holiday arrangements have had to be renegotiated in the light of Julia's current capabilities.

Future horizons

During the first two interviews, discussions of possible future impairments were mentioned but the conversation was curtailed, signifying a reluctance to dwell on what the future might hold:

Julia: For goodness' sake, we don't need to talk about that, 'cause it's not coming yet (regarding difficulty getting upstairs) (Wave One)

Julia: It is going to end in blindness, but there you go, bring it on (changes subject). (Wave Two)

However, over the course of the fieldwork Julia became more willing to discuss her future. Despite a comment during the final interview of *'there's no point looking at the end'* (Wave Three), she initiated a conversation about her wishes for future care with Peter and Eliza present. The meaning-making processes are evident in the excerpt of dialogue below, as they negotiate future action on the basis of meanings constructed about the end of Julia's life:

Julia: But the only thing I worry about and I haven't done it, is to get the ... erm... but the girls know that, don't you, you know about when it comes or when it comes or whatever, I don't want to be hanging around.

Peter: But you'd have to have that in writing

Julia: That's the only thing we really need doing

Eliza: If that's your wish you need to put it in writing, in writing so it's legal. 'cause at the end of the day it's your decision so you need to put it in writing and that's it.

Peter: Tell your GP and then...

Julia: *You know that!*

Eliza: *Yeah I know, but you know, things change [Peter: Yeah it's got to be in writing] you need to put it in writing because it's your wish, it's nothing to do with me, Dad or Naomi, it's up to you isn't it? [Julia: I'll do that] so if you are 100% then that's what you need to do.*

Julia: *Well why would you want to be hanging on, for God's sake (laughs). Don't feel badly about it... You know, I'll come and haunt you if you keep me hanging around (laughs)* (Wave Three)

As a result of her PCA Julia reported that she had lost her fear of death. During the second interview she described an intimate conversation with another person with dementia at a PCA support group meeting. In some respects, for both Julia and Louise from Family One, there seemed to be a sense of accelerated intimacy at the support groups; meaningful, trusting friendships seemed to be quickly formed. The quote below exemplifies an intimate conversation with someone who Julia had only quite recently met:

Julia: *We was having such a great conversation and we were right close like this to each other so we could hear it 'cause there were so many people in there, and we were in our own little, you know, time, and she said, just out of the blue, she said 'I'm not afraid of dying, are you?' and I sort of, I thought, and I said, 'well, I'm not afraid either' but before I had it, I had the most morbid fear of being put into the box and put into the ground and it would make me feel sick. You know but I'm completely, I have no worries... at all... it's like a big weight has been taken off because I have told my parents, whether they like it or not, and I don't know what it is, I don't think it's the drugs that's making me do it, I think I've just... I'm at peace, yeah, and nothing you know, really fazes me* (Wave Two)

Wong and Tomer (2011) have argued that little is known about how people move from a position of death denial to death acceptance. For Julia, extreme anxiety caused by the mental image of her corpse being enclosed in a coffin has transformed into a serene acknowledgment that death will occur: the final barrier to her equanimity, the disclosure of the diagnosis to her parents, has been overcome.

Motif: The social experience of dementia

Connecting with other people with dementia became, over time, a highly significant aspect of Julia's life, largely replacing her previous social life. During the third wave, Julia spoke about how general social events held less appeal for her, often experiencing them as over-stimulating and disorientating. She had stopped her long-term involvement in the Irish club, and, while she still participated in other social gatherings such as weddings, she tended to curtail her presence, and left as soon as she felt tired or confused, no longer feeling the need to comply with the cultural norm of staying at a wedding all day.

At the beginning of the fieldwork period Julia attended the general young dementia support group, but by time of the second interview she was engaging more with the diagnosis-specific PCA support group. The meetings became increasingly important to Julia, and she became concerned about people living with dementia who may not have access to this form of support:

Julia: It's absolutely great to go to these things, and I often worry if there... well, there must be millions of people who are sitting in their house, not knowing what to do, where to go, and it must be horrendous for them
(Wave Two)

Julia saw the purpose of the groups, then, as a means of preventing isolation. For her, they provided a space to forge new relationships and friendships, an arena where information could be transmitted and pleasurable activities such as meals and listening to music could be shared. As the fieldwork progressed, she began to talk more about specific individuals within the groups, the relationships that were developing with them, and their use of humour to co-construct shared understandings of their experiences: '*we have a right old laugh at our own expense!*' (Wave Two). Interestingly, on occasion the groups offered the opportunity to verify her difficulties to Peter; scientists presenting information at the groups, she felt, were positioned as experts by the spouses of people with PCA who sometimes de-legitimised their visual difficulties:

Julia: Lots of the other people (with PCA) who were there, they were aghast because they actually looked at their partners and said 'I told you!'
(Wave Two)

However, while Julia benefitted a great deal from the groups, her first experience was experienced as challenging; witnessing people who are at a more advanced stage of the condition can be unsettling, as the following quote illustrates:

***Julia:** She (attendee with PCA) was really horrible, talking to her (paid carer) as if she was a slave or something [**Peter:** She was quite far down the road I think]... she kept eating all the time and she wanted Guinness and she wanted crisps and that was the first time we went and I thought 'oh my God' you know and I hated it really, the first one... I look forward to them, I dreaded the first one I went to, and now I look forward to them, we all know each other*
(Wave Two)

Julia also made an observation about the limited diversity in the groups:

***Julia:** The strange thing is, you don't see any... people of our age who are, how can I say it, people who are like really really poor and they must have that sort of thing, in and around (the area), they must be here, but you never see people like that*
(Wave Two)

In addition, she remarked that men with PCA coped less well than women; particularly with needing help getting dressed. She also felt that some people in the groups needed 'a good shaking up' (Wave Three) because they lacked a positive outlook on life.

The groups seemed to engender a sense of dementia as a social identity. Although she remarked on the differences between all the attendees with PCA, she described similarities such as taking a long time to find things or to complete tasks, and feeling frustrated at not being allowed to do tasks by their partners. Belonging to the groups presented her with opportunities to gain not only information and emotional support, but also to reconstruct a sense of self which incorporates the social identity of young onset dementia.

Julia's Through-Line

Saldaña (2003) encourages qualitative longitudinal researchers to identify a 'through-line', a crystallisation of a participant's change over time. For Julia, there seemed to be a greater sense of acceptance of her condition, and a determination to make the most of the present, as the following quote illustrates:

Julia: I've got very brave since last time I see you because, you know, all the meetings that we go to, we go to, unless I'm not having a good day and we go out dancing and things like that, do you know what I mean, so anything... if Peter says to me do you want to go there, that's it, you know what I mean, I'll go, 'cause it's good, it's good for me (Wave Two)

While the present became more intense, she also became more willing to consider and talk about her future needs:

Julia: If I want to do it this way or that you know what I mean, there's no point in me thinking about it and not saying it to anybody, 'cause I might not remember and it's for you three to know (Wave Three)

She seemed to move to a more dementia-centric position, in that her social identity as a person living with dementia solidified; dementia-related activities became more important as general social activities lessened. Her regard for her parents' attitudes, and her sense of obligation to them, declined over time, as she perceived that their negativity and lack of acceptance had significant effects on her physical and mental well-being. At the same time, her relationship with Peter, her elder daughter and Peter's best friend and his wife strengthened. As she noted:

Julia: We're not surrounded, we're not surrounded by too many people but the people we've got, they're quality (Wave Two)

Attaining mastery of either tasks or physical health conditions became triumphs for Julia. For instance, she described her feelings at being able put on her bra as '*when I can do it it's like yay! How clever are you!*' (Wave One). As Sharpe and Curran (2006) have suggested, ill people redefine ways in which they assess success in order to re-establish an '*emotional equilibrium*' (p.1154) or perhaps to fortify their sense of ontological security. Controlling her diet to manage her diabetes, and being taken off her diabetes medication as a result, was also a highly significant event for her:

Julia: I was so happy, and I was so proud of myself, because I can't really do great things now, but that was a great thing for me (Wave Two)

Julia seemed to become less driven by emotion and developed a more rational approach over time. While she related instances of feeling angry and frustrated by her sense of her deficits, a commonly used phrase was '*what's the point?*', usually in relation to a potential

source of stress. She reported a greater sense of calm and her periods of feeling diminished as a person seemed lessened. Participation in young dementia groups and other dementia-related activities seemed to become more important but formal support from the hospital became less meaningful from Wave One to Wave Three:

Julia: Sometimes I wonder why we're going there really, because they don't really do anything, do they? (Wave Three)

Peter disagreed with Julia's viewpoint though, noting that it was the hospital that recognised she had developed weakness in her left-hand side, and that they had also made the referral to the occupational therapy department to enable them to get more aids around the home.

Peter

Orphaned at the age of 12 and relocated from Ireland to London to live with an aunt, Peter was working and living independently at the age of 16. He considers that he '*never had an education as such*', and has been '*through some dark places*' (Wave Two) but takes pride in the fact that he has always supported himself and his family through work and that, prior to Julia's PCA diagnosis, had '*never claimed a penny*' (Wave One) in welfare benefits.

Motif: Coping with transitions in the division of household labour

Although as a young adult he lived independently, once in a partnership with Julia, the division of household labour became traditionally gendered; while Julia had a part-time job, her predominant roles were perceived to be child care and household management while Peter worked full-time. When Julia developed PCA, Peter's role had to change to absorb new responsibilities:

Peter: The only (thing) I ever done was went to work, come home, put money in the bank, and Julia did everything, and when all this happened she couldn't do anything and I had to take the whole thing on' (Wave Two)

While at the beginning of the fieldwork, Julia was still able to clean the downstairs of the house and do some ironing, by the second interview she was not participating in any household tasks, with the result that Peter had to manage all the housekeeping: '*I do everything, everything*' (Wave Two). Because of the independence of his early adult life, coping with some of the tasks was not challenging, however, his limited education and consequent lack of confidence in spelling and grammar impacted on his belief in his ability to pay bills and fill in forms. As Julia noted:

Julia: *I'd go into the kitchen, open the cupboard, 'cause I was seeing OK, and I could sort of sort it out. I said 'Peter' I said 'you've got so many bills in here why don't you' and then he started and we'd have a bit of a row or something and I said 'look when you've paid one bill chuck it away!' And I thought 'Jesus he's not going to cope' and I don't think he was coping*

Peter: *That's what I'm like, I'll pay a bill and I'll keep that bill until the next bill in case there are any discrepancies*

Julia: *Yeah, that's what you do, but you was keeping them, you was keeping months' worth, Jeez* (Wave Two)

Although, with the help of anti-depressants, Peter felt he had '*got his head round*' (Wave Two) the household management, by the third interview, Peter's difficulties running the house had intensified, a fact he felt was not fully acknowledged by Julia:

Peter: *Although Julia thinks I don't do a lot, I'm on the go, seven days and seven nights a week* (Wave Three)

For Peter, respite had become increasingly necessary by the end of the fieldwork. He had arranged for Julia to go to Eliza's house once a week, for a one-to-one dementia support worker to take Julia out for one morning a week, and had decided to employ a cleaner.

Julia made attempts to negotiate a contribution to the completion of household tasks, as during the second interview she noted that she had offered to help. Peter, however, argued that it was more efficient for him to carry out the tasks himself:

Julia: *But I do try to help him but then he says [Peter: I'll be quicker doing it myself, I'll be quicker doing it myself] 'you miss bits, I'll be quicker' and I don't even argue with him, I say 'OK you go on and do it'* (Wave Two)

Increasing need for support

Over the course of the fieldwork, and particularly in the final three months, Julia's condition deteriorated, and her ability to remember events was beginning to fluctuate, as Peter noted:

***Peter:** Since we got back from Europe, her eyesight and everything has gone quite a bit, downhill, basically... over the weekend she asked me about three times when you were coming... But then when she woke up this morning and knew (you were coming) today. It's hit and miss a bit, more miss than hit*
(Wave Three)

By the third interview he felt unable to leave her on her own in the house for more than two hours, stating that it was unfair for her to be alone as she was no longer able to make herself something to eat or drink. During the first interview, Peter's discussions of support were limited to obtaining welfare benefits; at that time, other forms of support were not deemed necessary. However by the final interview he stated that he needed more assistance. Elder daughter Eliza had started to ring every day and looked after her mother for a few hours on her day off. She and her husband also often took her shopping or for lunch at the weekend. However, no similar transitions had occurred in the help offered by younger daughter Naomi, as Peter explains:

***Peter:** She don't ring every day, maybe once a fortnight unless you go down and see her, but she told me that if I ever need anything all I've got to do is ring her up but she'll never offer to take her mother out... whereas the other one who went off the rails a bit 'cause of what happened to her mother, she's back on track now and if she's ever off she'll ring her mother up and say 'look, would you like to come down here, would you like to go out, what do you want to do?*
(Wave Three)

Peter was very conscious of this difference between the active and passive forms of support from his daughters. He also benefitted from very active support from their close friends Colin and Celeste. Colin, his best friend for over forty years, arranged days out for Peter to give him a break from his caring role and arranged all the details of their holiday to Europe. As Burkitt (2008) has noted, friendships enable us to reflect on ourselves, facilitating an objective view of self. Colin's care for Peter may therefore be enabling Peter to view himself as a person experiencing strain and in need of support:

Peter: *He come up here and he pop in, him and his wife, and he looked at me and then I'll have a phone call two days later and he'll say 'me and you are going out today' and I'll say 'why?' and he'll say 'I think you could do with a little break'*
(Wave Two)

Peter: *They've got it all sorted out (the holiday) so I did say to them 'well, we don't know what Julia is going to be like' and all that and he just turned round to me and he said 'don't you worry about it' he said 'there's three of us to look after her'*
(Wave Two)

In the final interview, he described the extent to which his friends had supported him whilst they were away: *'they take over, I hardly do anything'* (Wave Three). Colin had arranged disability assistance for the train journeys, and Celeste took Julia to the toilet and helped to cut up her food. Colin also arranges days out for him and Peter while Julia is with her one-to-one support worker and Celeste stays with Julia in the afternoon, a form of support which they both described as *'brilliant'*.

In contrast, Peter has a very troubled relationship with Julia's parents, particularly her mother: *'I hate the ground she walks on'* (Wave Three). Despite feeling that he has helped them in the past, he considers that there is a lack of reciprocity, and believes that they neither like nor appreciate him. From Peter's perspective, Julia's parents have a sense of social superiority because of her mother's wealthy ancestors, and perceives that he, with his limited education and lack of affluence, was not deemed to be an acceptable family member. His dislike of her parents has intensified since Julia's diagnosis of PCA, since he feels that not only do they not accept her diagnosis, but that they can be actively unkind towards her:

Peter: *Sometimes she has trouble putting her boots on or sometimes her gloves, and... she couldn't get one of them on and he (her father) took it off and put it on and he said 'sometimes I think you're putting this on' and it's not a nice thing to say...*
(Wave Two)

Other aspects of her parents' behaviour that antagonised him were speaking about him as if he was not present, not showing any interest in Julia's experience of the support groups, and for not participating in the research. Like Julia, he perceived her parents to be jealous of Colin and Celeste for demonstrating so much support and compassion. However, despite their perceived negativity, Peter felt that he should still take Julia to visit them:

***Peter:** I'd feel guilty if I didn't take her down and they'd blame me for not taking her down do you know what I mean so I do it 'cause of that*

(Wave Three)

Peter noted that Julia's increasing dependency had led to a shared re-evaluation of their outlook and a shift in moral relationality. Prioritising themselves over others is perceived as a necessary stage in the process of managing Julia's PCA:

***Peter:** Well we've come to the conclusion that we do what we've got to do, we come first, Julia comes first, and the rest come second. That's the way... I never used to be like that, but that's the way it's got to be, I've got to look after her and anything else... but that's the priority is looking after her really*

(Wave Three)

Social experience of dementia

For Peter as well as Julia, the social experience of dementia seemed to become more important as the fieldwork progressed. However, a process that seemed to become particularly significant for Peter was reflecting upon the experiences of friends and acquaintances with PCA. While there was little explicit comparison with Julia's experience of the condition, there was a sense that Peter contextualised her dementia in the light of others' behaviour:

***Peter:** Unfortunately another chap, he has a similar thing to Julia and now he's been sectioned because he came in with a pair of shears and threatened to kill his wife twice... then there's a lady who we see, she was telling me (her husband) tried to strangle her a couple of times, but unfortunately these poor people don't know what they're doing sometimes. Then another little story I'll tell you is Neville... who won't admit there's anything wrong with him, and he's quite nasty towards his wife, it's the way things have changed over a year, he's gone downhill, which is sad really to see, because he was diagnosed at the same time as Julia and he was quite a nice chap*

(Wave Three)

Witnessing deterioration in the behaviour of others with PCA potentially creates both a relief that Julia is not experiencing those transitions but potentially also a foreshadowing, in that in observing others' presents, he may be observing Julia's future. Overall, from

Peter's perspective, his initial reservations about attending the groups have dissipated in view of his positive experience of building new relationships, and exchanging information:

Peter: *When we go to these things, 'cause Julia loves going, and we have a chat and socialise... we've got to know loads of people. There's other people there who are the partners' carers and we have a chat this and that... it's good for everybody...I was a bit dubious when all this come about, about all these meetings and stuff, but it was the best thing we ever did* (Wave Two)

The process of social recognition of Julia's difficulties created moral complexities for Peter, as initially he had asked his friends to lie about Julia's PCA to their wider social network. When signs of difficulties were remarked upon by a group of acquaintances to Celeste and Colin at a party, they prevaricated, describing the observed changes as merely age-related. For Peter, eventually being honest with people was experienced as a huge relief as it nullified discredited stigma (Goffman, 1963) and underpinned the message he wished to pass on to others in a similar situation:

Peter: *The thing I would recommend to anybody that if you're diagnosed with it to tell immediate family straight away and tell your friends so people know... 'cause we hid it for a while. There's no point hanging on...it's a weight off your shoulders 'cause you're not trying to pretend or make excuses for things that might happen* (Wave Three)

Eliza

Peter and Julia perceived that Eliza had initially been extremely distressed by the news of her mother's diagnosis, seemingly much more affected than her younger sister Naomi. Julia attributed their different responses to the fact that Naomi was a mother and was, as a result, '*more matter of fact*' (Wave One). For Eliza, however, her husband's development of leukaemia a few years previously created the context for her response to her mother's dementia:

Eliza: *It's a big shock isn't it, it's like anything, but I dunno... I had a big shock from my husband a few years ago so I think I was just thinking 'oh my God'*

Julia: *'Why me? Why me?'*

Eliza: *Yeah*

(Wave Three)

Eliza described herself as a '*proper mess*' when she was first informed of Julia's PCA, and the memory of learning about the condition is etched onto her mind together with a sense of frustration at her powerlessness:

Eliza: *I'll never forget the day they came round, Dad said 'can you turn the TV off?' I was like 'God what's the?' do you know what I mean, then me and Dad went outside for a cigarette, and we sat down and he didn't just tell me... yeah, took you ages to tell me, and (Julia) started crying, and I think I, I think I was in shock, do you know what I mean, for ages, and then once you look into it, I mean Dad's given me paperwork and stuff, I've like gone on the internet and I've looked into it. It is what it is, there's nothing you can do*

(Wave Three)

Making sense of Julia's PCA

Eliza has adopted Julia's means of objectifying the dementia as '*the shit*' and also felt that the condition had occurred at the wrong time in the lifecourse: '*she's too young*'. From Eliza's perspective there was a sense of having no choice other than to adapt and to learn to live with the condition, accepting that cannot be changed: '*it's not gonna get any better*', a perspective she shared with Peter: '*you can't go round with your head buried in the sand, things are not going to get better they are going to go that way*' (mimes downward slope). In the communicative practices of the participants, Julia asserted that there was honesty about the effects of her condition, rather than a sense of protecting them from the truth:

Julia: *I don't be upbeat and everything [Eliza: All the time] all the time, but I never just do it, just to make you feel better [Eliza: No] if I don't feel right then I'll say*

(Wave Three)

In terms of her own role within the family, Eliza had a strong sense of responsibility to support her parents but, like the participant in Bakker et al.'s (2010) study, also recognised the need to balance the needs of her parents with her own life:

Eliza: *You've just got to get on with it, I don't want to, you know, lose it, 'cause then I'm no good to Dad or you... you just need knowledge I think, and you just need to be strong, I think you just need information, and even if it takes three months or a year to get used to it, you still have to get on with your own life, 'cause you've still got your own stuff going on*

(Wave Three)

Accessing information about PCA

Eliza had read the written information provided by Peter and had also accessed the internet for further facts about PCA. However, for Eliza, the timing of the information was important, since the trajectory of the condition is difficult to predict. Her strategy of constructing the future as one day at a time may give Eliza a sense of greater control over the uncertain future (Charmaz, 1991):

Eliza: I've read it, I've not (gone) really deep into it, 'cause obviously some of the stuff that I read, Mum's not at that stage yet, so I don't know what's gonna... none of us know, do we, we just go each day by day

(Wave Three)

Julia has also accessed information about the progression of PCA, and, even though the family practices of the participants focus on acceptance of the reality of the condition, Eliza attempts to alleviate Julia's distress by suggesting that personal variation may not be accounted for in online information:

Julia: But when I was diagnosed with it, I still had my... computer so Julia goes straight to it and read it all and got right to the bottom saying 7-10 years, God...

Eliza: Sometimes it's not a good thing to read too much into it though

Julia: Well I've done it now, it was years ago

Eliza: Yeah but everyone's different aren't they, so...

Julia: Well I've always been like that, I've always... you know, I want to know, I'd rather know than being kept in the dark

(Wave Three)

Negotiating support for Peter and Julia

Although Eliza initially struggled to come to terms with Julia's PCA, once she accepted the diagnosis she provided regular support in proportion to Julia's increasing dependency. Telephoning every day, and looking after her mother every Monday, Eliza had also offered to provide additional assistance whenever necessary, eschewing the need for secrecy:

Eliza: Dad knows all he's got to do is phone me up and if I can do something, I'll do it, don't need to hide it from me, or be worried about asking me to do anything (Wave Three)

In contrast, younger sister Naomi did not appear to have increased the level of support for her family despite the progression of her mother's PCA. Eliza suggested during the final interview that the amount of care she was willing to provide needed to be renegotiated:

Julia: Our Naomi...she'll come in with either a child, or no child, and then have a little chat, then she'll go over to the bingo which is across the road, then she'll come back in, show us what they won if they won anything, then she's off, but if she can do something she will do it, but if she can't, she'll say she can't

Eliza: But the kids aren't small anymore, they're not babies... so it's like Dad said earlier she doesn't work every day, so you just have to write down what days she's got off and then maybe she could pop up here (Wave Three)

Eliza was also keen for Peter to re-engage with social activities at the Irish club, and suggested that Julia could stay with her or Naomi to enable him to have a regular night out, and that Naomi could sit with her mother to allow Peter to go shopping. Engaging Naomi to help more often, from Eliza's point of view, would enable Peter to continue to provide care for their mother.

Future horizons

During the third interview Peter, Julia and Eliza discussed plans for future care. Eliza had visited a local nursing home, but had been not been impressed by it: '*you're not going there!*' Additionally, Eliza strongly expressed the need for Julia to legally record all her wishes to prevent potential disagreement between her, Peter and Naomi:

Eliza: If the time comes and you don't want to be kept going for whatever reason then you need to put that in writing that's the only thing I'm saying to you, that's ... you know, do we do this, do we do that. I've got an opinion, Dad's got an opinion, Naomi's got an opinion, just whatever you want, if you wanna do that, then you just need to put it legally... tell your GP then none of

us have got any choice, and we'll all be happy 'cause it's your wishes [Julia: My choice, yeah] (Wave Three)

However, despite expressing her wish for her mother to make choices that they could operationalise, Eliza expressed relief that Julia was unlikely to be able to afford to go to Dignitas for an assisted death:

Peter: She did say, and this isn't a joke or nothing, of going to Dignitas if she gets too bad

Julia: The first thing I wanted to do was to get Colin to look it up and he looked it up and he told me how much it was... I thought 'that's a good thing to do', but it 'cause it's quite an awful lot of money so I think that might be going out of the door

Eliza: Good! (Wave Three)

Julia noted that she hoped to spare her family from having to make difficult decisions for her end-of-life care, and would prefer a quick death from cardiovascular disease. Peter, while conscious of the progression of Julia's PCA, felt that it was important to retain a normal life for as long as possible:

Julia: I won't put you through that, I'll just a mini something or other...

Peter: Well that's what I'm saying (she's gone downhill) the last three months, we don't know where we're gonna be in the next six months. But until that day comes, and hopefully it'll never come, we can carry on as normal

Julia: There's a lot of people in my family on both sides and they have heart attacks, so I'm thinking about that (Wave Three)

Eliza shares Peter's desire to maintain normality. When Eliza looks after Julia, they engage in everyday activities such as watching television or going shopping, or conversing while Eliza does her housework. Although the PCA and young dementia groups are open to family members, Eliza does not participate in them but acknowledges that they are very beneficial for her parents. Eliza, then, is very supportive of her parents but has chosen not to become immersed in dementia-related activities.

Freddie

When considering family relationships primacy is given to interpersonal connectivity; less attention is paid to the relationship between people and their pets (Gabb, 2008) despite the profound and highly complex connection that can exist between people and animals (Hurn, 2012). All three of the participants within this family recognised the significance of Julia's relationship with dog Freddie in the context of her dementia. Eliza described him as a 'life-send' and Julia recommended that *'everybody should have a dog, if they have this'* (Wave Three), noting that she drew comfort from sitting quietly with him during her bad days *'even if he's just coming up to me and sitting on my lap, do you know what I mean, like I give him a big squeeze'* (Wave Three).

Indeed, Peter observed that the companionable bond between Julia and Freddie intensifies when she has a bad day; the dog refuses to be separated from Julia's presence even when he is moved:

***Peter:** If Julia is having a down day he'll be wrapped round her back. And that's where he stays and you won't get him off of there. I'll pick him off, put him on the floor, he's looked at me and he's straight back... Whereas today, he doesn't bother... It's as if he knows when she's not feeling too good, it's one of those, it's really strange* (Wave Three)

In addition to being a comforting presence, Freddie has also fulfilled an instrumental role; on one occasion when Julia was alone in the garden and became disorientated, Freddie went to find Peter and brought him outside to her. In addition to his comforting and functional roles, Freddie also gives Julia hope of a greater degree of independence:

***Julia:** I'm not allowed to go (to the park) on my own but I'm sure one day I will, when Peter's gone somewhere, 'cause it's quite straightforward to get to the big park and I'm sure the dog will be able to bring me home* (Wave One)

Summary

In a similar way to Family One, in Family Two there are relational practices which continuously assert and reassert who 'belongs' to the experience of dementia. For Julia, as her dementia advanced, she became more determined to spend time with those who

demonstrate affection and care for her; in her own words, '*quality*' people. Her moral sense of obligation to her parents waned over time because she did not perceive an improvement in their attitudes towards her, her dementia or Peter. Her dementia, then, did not, at least during the period of the fieldwork, become a reason for resolving the conflicts in what was an '*enduringly problematic*' family relationship (Smart, Davies, Heaphy & Mason, 2012, p. 92) but provided a conduit for the expression of conflict.

In contrast, Peter, despite harbouring an intense, sedimented dislike of Violet and Jonathan, still retained a obligation to visit them, and perceived that his own moral character would be cast into doubt if he did not do so. His statement '*it's what people think*' is suggestive of Mead's notion of the 'generalised other', an impersonal standpoint representing internalised societal moral principles by which we can be judged (Burkitt, 2008). Thus, in Family Two there seemed to be a moral 'weighing up' of family obligation on the one hand and personal well-being on the other, with differing outcomes for Peter and Julia. Temporality suffuses this deliberation; as the fieldwork progressed, Julia's determination to make the most of the present, and to be less inclined to spend time with her parents intensified.

The relational practices of others, notably Celeste, Colin and Eliza were valued by Julia and Peter, and continually reaffirmed their belonging to the experience of dementia. Julia's brother and sister-in-law, and her grandchildren, were also connected to the experience, albeit in a less intense way. Daughter Naomi seemed to have a passive form of involvement, which continued throughout the fieldwork, although Eliza and Peter hoped that she might become more actively supportive in the future.

Julia and Peter's membership of dementia support groups, while providing a means of creating a valued supportive identity characterised by shared intimacy, humour and information exchange, also creates a space within which others at a more advanced stage of dementia are observed. As the fieldwork progressed, stories of others' deterioration or death were described more often, as if their present was foreshadowing Julia's future. There was a sense of weighing the benefits and disadvantages of belonging to the groups, with early experiences being perceived as disconcerting; however, the development of

intimacy within the groups created a social space that increasingly seemed more appealing to Julia than general social events.

Chapter Eight : Family Three

Table 5: Family Three Participants

Generation	Participants All interviewed as a family group	Waves of interviews			Family members/ friends not interviewed
		1	2	3	
		Aug 2014	Feb 2015	Aug 2015	
Parents of person with young onset dementia					Joy
Generation where one person has young onset dementia	Francine, <i>living with Semantic Dementia</i>	✓	✓	✓	Francine's sisters
	Ron, <i>her spouse</i>	✓	✓	✓	
Adult children	Laurence	✓	✓	✓	
	David	✓	✓	✓	
	William	✓	✓		
	Marie (<i>daughter-in-law, married to Laurence</i>)	✓		✓	
Grandchildren					6 grandchildren <i>aged between <1 year and 12 years old</i>

Francine

Francine was diagnosed with semantic dementia at the age of 57 in 2013. She is married to Ron, who is step-father to her three sons Laurence, David and William. She has four granddaughters and a grandson, and became a grandmother for the sixth time during the period of the fieldwork. Her mother and two sisters, one older and one younger, all live within a few miles of her home.

Francine worked full-time as the manager of a clothing section in a high street retail store for over thirty years prior to her retirement several months after her diagnosis of dementia. She expressed relief at retiring but her association with the store remains strong; she attends the monthly event for retirees, regularly shops there, maintains friendships with former colleagues and makes frequent references to the store throughout all three interviews, suggesting that her identity as a former employee remains a significant element of her sense of self.

Motif: Struggling to manage at work

Francine had been a popular, conscientious manager. Eldest son Laurence noted that his mother was '*always rushing around*' at work, while Ron described her attitude to work as '*very focussed*'. Francine herself noted that:

Francine: *They all really did...like me as a manager and they all [Ron: Yeah, they definitely did] and they sort of really miss me 'cause I was always one that'd work with them* (Wave One)

Like Louise (Family One), and some of the participants in Johannessen and Möller's (2011) study, Francine's first indication that something was wrong occurred at work, when she started to have difficulties assisting customers and adapting to new technology:

Francine: *I decided to retire because I was just so nervous of making mistakes, which I was [Ron: You did start making mistakes at work, didn't you?] I did, yeah, and when customers ask you for things they don't want to understand that I couldn't say what it was, or where it was, and everything's starting now on computers, so I just can't do computers so I was glad I retired in that sense* (Wave One)

The difficulties at work caused her to doubt her capability as a hard-working, competent employee. This threat to her identity combined with the lack of an explanation of the cause of her difficulties began to create a great deal of distress. Receiving a diagnosis helped her to rationalise the problems:

Francine: *That's why I was getting stressed working, 'cause I was thinking 'why can't I do this anymore, why can't I log on to the computers, why can't I do*

that?' but once you know what it is at least you feel 'oh right, that was the reason why I couldn't do it', and it's best to know (Wave Two)

Francine felt that if she hadn't have sought the diagnosis, she would have faced increasing struggles at work, and would have further doubted her sense of self as an able worker: *'I would have got thinking "oh, you're blooming stupid, what do you keep doing that for?"'* (Wave One).

Despite her expressed relief at retiring from the store, in the final interview she wondered whether she might have been able to retain her job longer with support from her employer:

Francine: *I always think with my job, if they'd have took me off of computers and not on the till, 'cause I was always given a high thing for cleaning, I was always getting like 99%... if they'd have kept me on that, I might have stayed longer* (Wave Three)

Shortly before the final interview Francine had received a formal assessment from the Department of Work and Pensions to evaluate her capacity to work. From Ron's hesitation when describing their experience it seems that the official confirmation might have been difficult for him to accept, as he reframed the official recognition of Francine's inability to work with the lack of necessity for her to work:

Ron: *In the end they wrote back and said that she could no longer work... she, she, she... they didn't say she could no longer work but basically she didn't have to work*

Francine: *No, it said I couldn't work*

Ron: *Yeah, no... it must... (hesitates) if you know what I mean* (Wave Three)

Being diagnosed with dementia

Problems were also beginning to emerge at home; Ron had started to notice her occasional use of the wrong word for items around the home, for example, the use of the word 'watch' when referring to a mobile phone. The process of receiving the diagnosis

was experienced as a 'kick in the teeth' (**Ron**, Wave One), and, in particular, encountering the image of her brain from her MRI scan was distressing for Francine:

Francine: *When we went back for the results they showed me my brain on the computer and my left brain is real small, getting smaller, and it's got full of water and that's why it'll go down gradually, but they did say it can go to the other side as well... I just hope my brain doesn't get any smaller now, 'cause that's the bit, when they say [**Ron**: It won't, Francine] well it was a shock when you see it on the computer, when they showed you the left and the right side, the difference, wasn't it? It was a shock* (Wave One)

For Francine, constructing meaning of her dementia was compounded by the rarity of the condition. Unlike Alzheimer's disease, there is no medication which can be given to slow the progression of semantic dementia, and, in general, less is known about the trajectory of the condition over time. The wide time frame of life expectancy compounds the uncertainty faced by the family:

Francine: *It's a very rare one, so I think that's the worst one, when you don't know what's going to happen...I think the sad bit is not knowing how I'm gonna get, and how long I'm gonna be alive, 'cause when you see it, they say roughly 1 to 15 years [**Ron**: And you don't know] and you don't know [**Ron**: You don't wanna know, but what you don't wanna know is the one year] ... how long you're gonna live, that's what I sort of keep thinking, how long am I gonna live...* (Wave One)

Encouraged by Ron and her sons, Francine reported that she was striving to maximise her enjoyment of the present, rather than worry too much about the future. However, worries about her life expectancy continued to preoccupy Francine, as she noted in the final interview:

Francine: *You do worry about how long you're going to live, I don't want to (die) 'cause I want to be with my children and my husband* (Wave Three)

The lack of knowledge about possible causes of semantic dementia was also a concern for Francine. In particular, there was an continuing anxiety, expressed in all three interviews, that her current use of medication for migraines may have caused her dementia. In the first interview she reported that the dose had been reduced in response to these concerns and the hospital had asked for her permission to review her medication history. However, by the time of the second interview, and after experiencing an increase in

migraines, she reported that she had been informed that there was a possible link between the medication and Alzheimer's disease rather than semantic dementia and that she could return to her usual dosage. Nevertheless, she continued to be concerned about her use of medication and did not seem entirely convinced by her doctor's reassurance by the time of the third interview:

Francine: *The doctor at (name of hospital) said that amitriptyline could be what causes... erm, what is it, is it the other one, not dementia, Alzheimer's, that's the thing. [Ron: Alzheimer's] You just don't know what causes it, do you? Is it the medication? It's sort of a worry if you've got medication*

(Wave Three)

Motif: The maternal role, and the inability to choose which memories remain

Francine's identity as a good mother seemed to be a central aspect of her sense of self; she and Ron frequently referred to how she had brought her sons up despite a problematic relationship with their biological father. Even as adults, she regularly brought them food and she perceived that they remained a close family:

Francine: *I've been really close with my boys, haven't I? You know, I've got some lovely boys and we're really close and yeah they're always there for me*

(Wave Two)

A recurring theme throughout all three interviews was Francine's sorrow at having forgotten some of her sons' biographical details, for example, their friendships and their time at school. Her sons often teased her during interviews about their strict upbringing, reminding Francine about aspects of her parenting style:

Francine: *It's just a shame when I don't remember everything from my own children what I did, though you tell me don't you? You had to be home at 9:30 you said at night, didn't you?*

David: *That was late, Mum. That was when I was about 12, then when I was 18 I had to be in by about 10 yeah!*

Francine: *It's just remembering bits like that, it is sad.*

(Wave Three)

For Francine, there was an ongoing sorrow that, as a result of her semantic dementia, she had lost memories she wanted to retain, such as those from her role as a mother raising

her children. In contrast, memories of difficult or traumatic times remained, and it was a cause of frustration that she did not have the ability to control which memories were retained and which lost. Her dementia, then, was potentially viewed as a way to recast her biography, a means of editing out bad memories but retaining favoured ones, but she perceived herself to have no control over the process. Her memory of unpleasant events appears to be a revelation to Ron:

Ron: *You've probably got a reasonable long term memory but a bad short term memory, I think. You know, she can remember quite a few things in the past...*

Francine: *Sometimes I remember bad things*

Ron: *But not bad things*

Francine: *I do remember bad things*

Ron: *Oh you do remember bad things, don't you?*

Francine: *I do remember bad things... You know, it's just those bad things for some reason*

Sue: *You remember those...*

Francine: *It remembered me. But yeah, it's like what I did with you children, I forget what I did at school and stuff, you know, what I did with you lot*

(Wave One)

Ron demonstrated concern for the effect of retaining bad memories on Francine's state of mind. For example, in the third interview, he revealed that, some years ago, he and Francine had asked his son to leave the family home. He had recently visited his son and observed that the visit had re-awoken difficult memories for Francine, resulting in an adverse effect on her mental health:

Ron: *When he was younger, we had to ask him to leave, and erm Francine keeps thinking she might have been to blame for that...I went to see him this weekend... Francine asked me all about it and, you know, she was saying 'well, is it my fault?' I said 'No, Francine, it's not your fault', and that plays a part of a bad memory that doesn't need to be stored, but you can't wipe it out, but she's got to feel no guilt... but you feel guilty really don't you? But she's not guilty so that doesn't help her depression so I wish I hadn't gone down now, but it's things like that, if things are bouncing around in her mind about things in the past*

(Wave Three)

Ron's desire to protect Francine from feelings of sorrow or regret may in future lead to a reduced or possibly secretive contact with his son. Thus this is an example of a unexpected way in which dementia might affect family relationships; if Francine were, in future, to forget her involvement in her stepson's departure from the home, then Ron may be able to spend more time with his son.

Heritability

A further cause of distress for Francine relating to her dementia and her role as a mother and grandmother is whether the condition might be heritable. One of her granddaughters has a congenital health condition which caused an under-development of the left side of her brain, and Francine worried that this was the result of a genetic abnormality. By Wave Two, Francine had been assured by doctors that, despite both conditions affecting the same hemisphere of the brain, there was no genetic link between them.

A persistent theme throughout all three interviews was the fear that she might have passed on a genetic abnormality to her sons, and that they or their descendents might develop semantic dementia in the future. In general, Francine perceived that '*we don't know, it's best not to think about it*' (Wave Two) but retained hope that no-one else in the family would develop semantic dementia.

Motif: Loss of confidence

One of the abiding, most distressing issues for Francine was a loss of confidence in her competence, skills and in her ability to make decisions. One of the key ways in which her difficulty making a decision manifested itself was in her choice of clothing. As a former manager of a clothing section, clothes seemed to have played a significant part in Francine's life; she demonstrated pride in her ability to colour co-ordinate her outfits and enjoyed looking smartly dressed. Having difficulty deciding what to wear was clearly challenging to her:

Francine: *Yeah I can't make decisions [Ron: Yeah she can't make decisions at all, she gets...] 'cause the boys know what I've always been like about clothes but I now make decisions of what to wear, and I'll show you things won't I? (to Ron) and he'll say 'that looks nice' but then I'll change and put something else on*
(Wave One)

In subsequent waves, Francine reported that that her problem choosing what to wear and colour-co-ordinating her clothes persisted, and that increasing amounts of time had to be devoted to getting dressed. Fear of making mistakes, and breaching social norms, seemed to be at the heart of Francine's loss of confidence, and her clothing choices seemed to symbolise this concern. Young onset dementia is a condition with fluctuating visibility, which may, as Joachim and Acorn (2000) suggest, be more challenging to deal with than either permanently visible or invisible conditions. A lack of predictability of when difficulties might occur can potentially destabilise ontological security, compounding the experience of distress.

As the fieldwork progressed, Francine described increasing periods of feeling down and crying. She reported worrying more about symptoms of physical illness: *'When I've got a bit of a bad throat and stuff, when I get that, you start thinking "oh my God" 'cause you worry about getting cancer'* (Wave Two). At the beginning of the fieldwork period she reported being nervous of new experiences, but by the end, she had started to become anxious about regular social occasions:

Francine: *I'm nervous, I'm nervous going to (name of support group), the evening things, I'm nervous of them all now, for some reason... but I am, in case I do anything wrong, I think.*
(Wave Three)

The emergence of her dementia in social interaction was distressing for Francine; for instance, forgetting the names of former colleagues affected her confidence:

Francine: *I think the most embarrassing bit is when people say 'Hello, Francine' and I don't remember who they are. I hate that... I see them once a month, I still don't remember their names and I get really frustrated over that... I do know them, but I don't remember their names, I have to ask them, but they understand what I've got, so they know why I ask*
(Wave One)

The effects of her dementia on family practices was also troubling for Francine. Her identity as an active, engaged grandmother was threatened by her inability to draw pictures of animals for her grandchildren to colour in:

Ron: *Francine is starting to get a little bit frightened when they ask her to draw something... she wants me to be here to draw... she doesn't want to look stupid in front of the children or make them think 'well, why doesn't Nannie know this?'*
(Wave One)

Francine: *When they ask me to draw stuff and I don't know how to do it that gets me down 'cause I think 'Oh God I don't know what it is they want me to do'. I wish I could know what they want me to do, you know?*
(Wave Three)

Accidents at home and in the community also caused Francine to lose confidence in her ability to manage everyday life. Injuring herself with the strimmer and the iron, forgetting meetings, getting diesel on her coat at the petrol station and forgetting her debit card when shopping increased a sense of losing control over her ability to perform the activities of daily life. Interestingly, she ascribed all the difficulties she experienced to her dementia, whereas other family members, particularly middle son David, tended to normalise these kind of problems. Despite her family's attempts to reassure her, and to normalise the difficulties she faced, Francine remained distressed by her anxiety and loss of confidence:

Francine: *I am really nervous about things, and I get annoyed because I can't remember anything now. I have been crying a lot*
(Wave Three)

Motif: Constructing a social identity of dementia

Francine and Ron were regular attendees at young onset dementia support groups. Francine typically attended the day time groups alone, and Ron accompanied her to the evening social events. The rarity of her dementia seemed significant, and potentially isolating to Francine; at the start of the fieldwork period, Francine commented '*nobody there's got what I got, have they?*' (Wave One) and by the end of the year only knew one other person with semantic dementia. In the first interview she talked briefly about her attendance at the groups. However during the second and third interviews she described

the attendees in more detail, considering her own future in the light of their observed deterioration:

Francine: *You can see some people and they're getting worse, they look worse, you can tell by their face and stuff, and how they talk and stuff, so a lot of them don't seem to talk when they're worse, they can't talk, so I think that will probably be a thing later* (Wave Three)

Like Peter (Family Two), she was acutely observant about others in the group, the ways in which they behaved, their changes over time and the sense that in observing them she may be getting a preview of her own future. On two occasions she referred to a woman who attended the group 'in a cage' and who had to be fed by her husband and son. Additionally she mentioned a man who had to retake his driving test, initially passing but then failing the second time. Like some of the participants in Johannessen and Möller's (2011) study, worrying about losing her ability to drive was of concern to her.

Francine: *I think what worries me when you see other people with what I've got and how bad they're getting and then it makes you think 'oh God I hope I don't get like that'* (Wave Two)

Francine's developing social identity of dementia also emerged in other ways. While her habit of watching television had diminished as a result of dementia 'I don't take it all in' (Wave Three), she made an exception to watch programmes about dementia. She also read leaflets and newsletters and told her sons during interviews about other peoples' experiences of semantic dementia. In addition, she had joined WeightWatchers due to an online report Ron had seen about weight gain:

Francine: *They're getting fatter, dementia people... that's why we still go to WeightWatchers so I can keep it down a bit* (Wave Three)

It appeared that Francine was trying to engage her sons with her developing identity as a person living with dementia, not only through sharing the newsletters with them but also by inviting them to support group events. During the interviews, her sons did not respond to her suggestions:

Francine: *Well what I thought, you know that dementia evening, I thought I'd like you boys to come at one stage and then you'll know what it's like, it'll be good, wouldn't it, 'cause people do take their children there* (Wave Two)

Francine: *I went there on Monday, 'cause you know (turning to Laurence, David and Marie) you can always turn up if you want to, anyone can come with me if they want to* (Wave Three)

The support groups afforded opportunities for Francine to develop new relationships and have new experiences. Francine described how the support workers were actively trying to encourage people with dementia to engage in new activities, and during the third interview, she described how she had contributed to a collage which was displayed in the local museum. In addition, she had started colouring in pictures of clothing drawn by one of the support workers:

Francine: *'Cause they know I'm into my clothing, she drew that (shows picture of pencil drawings of items of clothing) and I had to colour that in, 'cause they know I'm into clothes and they all say I look lovely in clothes!* (Wave Three)

However, while she found the activities and the support very helpful, she appeared to be discomfited by the offer of one-to-one support, a service where a support worker visits a young person with dementia for three hours a week and assists with any activity the person might want to do either in the home or the local community. From Francine's perspective, the one-to-one support was not appropriate at her stage of dementia; she perceived a disparity between her and the charity's view of the progression of her condition. She appeared to feel a little harassed by being asked:

Francine: *I don't feel I need it...'cause they keep asking me all the time, they do...they will keep asking all the time* (Wave Three)

Strategies

Francine and Ron had negotiated a range of strategies to alleviate her anxiety. For instance, writing messages to remind her to collect her granddaughter, using a calendar for appointments, cooking packet meals with written instructions, and staying near to Ron in busy public places as her sense of place became disrupted by dementia:

Francine: *When I go to the airport, if I need to go to the toilet, he has to stay near me 'cause I get worried I won't know my way back to where he is [Ron: That's right] and even though I've been to the airport a lot of times, I like to hold his hand* (Wave One)

In addition, being no longer able to drive was expressed as a concern for Francine: 'eventually I might not be able to drive, that's the sad bit' (Wave One), and Ron had bought a new car to assist her:

Francine: *I do go by the car he's got me, it comes up with a speed now, 30, 31 or whatever, so it's a lot easier [Ron: Big numbers] for me to drive so I can see I'm not going over speeding or anything, and ... he sort of says to me now, 'what's that sign mean?' so I'm trying to learn the signs to make sure that I don't forget what it says... I do them right, so yeah, not too bad am I really?*
(Wave Three)

Every time I arrived at the house, more family photographs had been added to the ones already displayed in the living room. Ron explained this as follows:

Ron: *You see loads of pictures and that's because Francine has put them up, don't get me wrong, I love them being up, and she wants a lot more put up elsewhere, so she can see, and be reminded, 'cause she thinks she might forget, and she's not. That's why she's done it, so it's a good tool, isn't it?*
(Wave Two)

In addition, Francine seemed to spend more time looking at photograph albums:

Francine: *My picture books...I was looking, well it just makes you remember it all then doesn't it, of what they all were and stuff, so yeah, there's loads of photos there of the kids... when you start going through the pictures, I do like to go 'cause I don't remember a lot of it*
(Wave Three)

During the first interview, Francine noted that she had been advised by the support workers to get a dog 'cause it gives you something to do', and she bought a puppy before the second interview. Having a dog encouraged her to go out for walks when Ron was at work, although the responsibility of caring for the dog, and preventing the dog from biting the clothes in her bedroom also caused some anxiety 'I do worry if I'm ill at any time that I can't cope with her' (Wave Two).

Relationships with her Mother and Sisters

Francine's mother and sisters seemed, from her and Ron's perspective, to have little understanding of the effects of her dementia on her capabilities. Her mother Joy was

recovering from a long-term illness, during which, according to Ron, Francine had provided most of the care:

Ron: *It put a lot of stress and pressure on Francine actually, because her sisters expected Francine to do a lot and she wasn't mentally capable. She was physically capable, Francine is, but she didn't feel mentally capable*
(Wave One)

In addition, Francine perceived that the ongoing arrangement for the three sisters to take it in turns to look after their mum for a day at the weekend had been 'dictated' to her, and, moreover, that her sisters would lie about weekend arrangements to ensure that Francine looked after Joy at their convenience, disrupting her own arranged plans. Francine reported that there was a breakdown in the relationship between her and her younger sister that occurred several years before her diagnosis, but that unfortunately her dementia had not changed her attitude towards Francine: *'it's just a shame that the younger one ain't changed, she's horrible'* (Wave Three).

Francine's mother appeared to have a lack of understanding of Francine's capabilities:

Francine: *She wanted me to take her on holiday, she did, abroad. She like expected me to take her on holiday abroad but I said, 'Mum, I can't do that, I can't do that anymore'... I wouldn't do it (in the UK) now. I'd worry I'd get lost and that*
(Wave One)

Eldest son Laurence perceived that Joy would compete with Francine by comparing their respective illnesses and would believe that she had more problems to contend with. According to Francine, Joy seemed to de-legitimise Francine's memory loss by stating that she too was having difficulty remembering things. *'I said, yeah, but you're a lot older than me, Mum'* (Wave Two).

Spending time with her mum was stressful for Francine, as Joy often referred to Francine's younger sister:

Francine: *All she talks about is her daughter, her husband, and all that, and I said to Mum 'can you not keep talking about it? 'cause then it gets in my head about them more which I don't want. I don't want it to. But she does, doesn't she?*
(Wave Three)

Future horizons

With the help of the support worker Francine and Ron had made efforts to control the sons' future inheritance. They had made wills, and changed the ownership of the home to ensure that Laurence, David and William would be able to inherit some of the proceeds from the house if Francine went into a care home in the future. However, Francine's perception that her mother had a closer relationship to her sisters than to her had potential ramifications in that, should she predecease her mother, her share of her mother's money may not be inherited by her sons:

***Francine:** Hopefully not, but if I went before my mum, she said then the money goes to my three boys but you don't know, do you, 'cause it could change... I wouldn't want my younger sister to have all that 'cause she doesn't have nothing to do with me*

(Wave Three)

Going on holidays and making the most of the remaining time seemed to become an increasingly important priority for Francine and Ron. During the period of the fieldwork they went on holiday for the first time with friends, with plans to go away with them on a regular basis; friendships, therefore, seemed to become more important to them over the course of the fieldwork period.

Ron

Ron, 62, is a manager at a construction firm and has been married to Francine for 23 years. Shortly before the third interview Ron was offered, and accepted, voluntary redundancy. He appeared very loving and considerate towards her and confirms her commitment to her close family: *'they (the grandchildren) like, love being with you don't they? [Francine: Yeah, they do] that's one of the great things, you know, she's a lovely, great Mum and a great grandmother and wife* (Wave One).

Motif: Trying to put things right

Striving to solve problems experienced by Francine as a result of her dementia and learning to cope together is a recursive element of Ron's accounts. He noted that one

challenge to their communication is that Francine seems less able to distinguish between minor irritation and anger, as the following quote shows:

Ron: *It's just if sometimes a word goes wrong... sometimes I find it a bit frustrating because I don't know.. so then I answer in a different voice, and if I answer in a different voice, Francine thinks I'm shouting at her, but there's a difference between talking in a different voice, and shouting. I try to tell her, you try to question, or put right, or say well it wasn't this, it's this, and so we're learning to cope with what Francine has got, together* (Wave One)

By the second interview, this difficulty seemed to be increasing 'it's getting quite a lot, where that happens' (Wave Two), which he perceived to be a lack of confidence in her actions so that she assumes she has said something wrong to invoke anger or disapproval. Ron appears committed to trying to improve Francine's confidence and encourages her to remain engaged in social life, reassuring her that mistakes she might make are minor:

Ron: *We went to (a cafe) once for a coffee and things didn't go quite as smoothly 'cause I tried to get Francine to buy the coffee, only to make sure she's interacting with people 'cause [Laurence: 'cause you're tight, that's why! (laughter)] I pay for it.. no, we take it in turns to pay for it but it's really to keep her confidence up and interact and something went wrong Francine and you had to go and sit down, didn't you? But it wasn't that bad, it was just something didn't work quite right and erm you felt that it was you, but it wasn't* (Wave Two)

When faced with difficulties caused by her dementia, Ron described his attempts to 'put things right' by discussing the event and trying to rebuild her skills and capabilities. While the sons and daughter-in-law Marie felt that the problems caused by dementia only occurred occasionally and with minimal impact, Ron presented quite a different picture:

Francine: *I just say to ignore me now, if I say something wrong, just laugh about it*

William: *I think you worry, I think you worry too much.*

Laurence: *You worry about it.*

Marie: *You think it happens more often than it does.*

Ron: *You say that Marie, but because you're not here all the time, Marie, it actually does happen more than you know, but... it probably happens more*

than I know, because we live with it all day, and every day, but you do see a little bit disappear... you know, that little bit, it disappears sometimes, and Francine knows it, and we know it, we talk to each other, and feedback to each other, 'cause Francine doesn't... I try to teach her again (Wave One)

Observing the signs of Francine's dementia

From the quote above it is apparent that Ron is alert to signs of Francine's dementia, even if he admits he would not observe every instance. In the home environment, he had noticed use of the wrong words for common things, such as nails instead of knees. In addition, he felt that Francine had difficulties remembering the content of conversations with her sons or of television programmes and had started to read things out loud *'even so I know as well'* (Wave One). One issue that seemed to trouble Ron, and to a lesser extent her sons, was her habitual re-arranging of clothes:

Ron: *One of the things she's been tending to do is always sorting her clothes out, always, you know, this week it'll be sorting this out, next week it'll be sorting that out, and then going back to it again, it seems to be repetitive, even through mine, which is fine, it's great, she's made a good job of putting all the colours and that together, but she's got into a thing of everything must be orderly* (Wave One)

In a sense, it might be this habit of Francine's recreates her working life as a manager of a clothes section in the home, giving a sense of order to the disruption caused by her dementia and subsequent retirement.

In public areas, Ron noted that Francine struggled to orientate herself when leaving shops, had difficulty remembering the names of acquaintances, had stopped observing the environment when walking and started to lack confidence in busy areas such as the airport:

Ron: *I could see her looking around, she was actually taken aback by it all, it just seemed, 'what's all this?' You could see it in her face, and it was a bit of a shock* (Wave One)

Having attended all the hospital appointments with her, he was able to recount detailed observations of the tests that have been carried out. In common with Francine one of the

turning points was the image of her brain showing the deterioration in the left hemisphere of her brain. However, unlike Francine, he felt that, on reflection, the image was not quite so shocking:

Ron: *It's actually not as bad as what Francine thinks, I think once you've seen the picture once you think 'oh my goodness', but when you've looked at it again, it isn't...it really isn't as bad as... you can see there's something there, but it isn't 'oh it's all gone'* (Wave Two)

Another turning point was when Francine was asked to draw a clock during her tests:

Ron: *Basically she drew a funny shaped thing and put numbers all the way round the outside but they weren't in the right place, and that's when it, you know, it really decided* (Wave One)

By the final interview, Ron noted that the doctors had observed a very slight decline in her abilities, which he concurred with *'you're forgetting more, but it's progression'* (Wave Three). During the first interview, Ron normalised Francine's forgetfulness, but by the final interview, rather than normalising it, he minimised the importance of remembering words in general:

Ron: *I'd like to say that Francine does that (forgets names) but I work with people I've worked with all my life and I forget the name of the bloke in front of me* (Wave One)

Ron: *All I say is, yeah, you forget, we put...we try to put it right, but the main thing is your health's OK. It doesn't matter what you forget. We try to really ignore it in a way... although she says to me afterwards 'I've said something wrong' and I said 'well OK yeah, you did, but it didn't matter', 'cause it doesn't matter, does it, you know, it really doesn't matter* (Wave Three)

Motif: Gathering and managing information

Of all the participants, Ron appeared to be the one who had most actively sought information about semantic dementia, sometimes challenging the knowledge of the hospital specialists. He was aware that Francine worried about having passed a genetic flaw onto her descendants, and had searched for information online. The following excerpt from the second interview demonstrates Ron's role as the information gatherer

and custodian. From Laurence's point of view, the conversation may be particularly poignant as he had recently become a father for the first time, and was holding his four-month old daughter while speaking:

Ron: *You do worry you might have passed something on to your boys don't you?*

Francine: *You do, you don't know with your family what goes on, do you?*

Laurence: *It's meant to be hereditary, isn't it?*

Ron: *They say no, they say no, but when you read about it...*

Laurence: *They say no, do they? Who says no?*

Ron: *The specialist, but when you actually read about it, a bit deeper*

Laurence: *It potentially can be?*

Ron: *It depends on how you interpret stuff, I suppose, at the end of the day*

Sue: *You've read quite a bit, Ron?*

Ron: *I think so yeah*

Francine: *He goes online*

Ron: *I don't, I don't (communicate it)... I keep it to myself*

Francine: *Do you? You know more than I think you know?*

Laurence: *There's going to be a lot of stuff on the internet, isn't there?*

David: *Ron you shouldn't keep it all to yourself, you should tell me, Laurence and William*

Laurence (to David): *You can read on the internet*

David: *Yeah but Ron don't want to get worried if he sees something, he wants to talk about it as well*

Ron: *It's nothing... it's just to be understanding to the illness more rather than something to say 'oh look your mum's going to be not here tomorrow morning' or something, it's to have an understanding David, so it's just a bit of deeper reading*
(Wave Two)

It would appear from this excerpt that the family members had not really discussed the likelihood of semantic dementia being a heritable condition before, and, indeed, there

was a general sense that the research interviews were occasionally used as a vehicle to discuss difficult topics not previously broached within the family. The repeated questioning from Laurence suggests that he views Ron as the key information source within the family. This is corroborated by youngest son William, who, describing how he reacted to the diagnosis in the first interview noted that:

William: *We was all upset, but I mean I was trying to understand 'cause like when I was told it's a different form of dementia - I know what dementia is, I was trying to understand it, it's like Ron helped, you know, explained it in depth so we know what form she had* (Wave One)

It is also apparent that Ron demonstrated a lack of trust in the specialists' knowledge and sought further information himself, and yet chose not to share it with the family. It seems, as the conversation progresses, that he retreats from discussing the issue of whether the evidence supports the notion that the condition is hereditary. After admitting that he doesn't share what he learns with his wife or his step-sons, something which comes as a surprise at least to Francine, Ron seems to minimise the significance of the information he has discovered, suggesting instead that his efforts to find information are merely to acquire a greater understanding of the condition.

It is significant that David did not include Francine in the group of people Ron should tell if he discovers worrying information about the heritability of semantic dementia. This suggests that he has a desire to protect Francine from further worry, and possibly prevent guilt she might experience if she believes that she may have potentially passed on a genetic flaw to her descendants.

Social identity of dementia

Like Francine, Ron was also very observant of others at the support group, and compared their experience of dementia to their perceptions of others' conditions. During the first interview, Ron expressed the view that they were less affected than many others:

Ron: *The rest of the people they've all got different forms of dementia, so there's a lot of people who are far worse than Francine is, in fact, we're probably the better ones at the moment, aren't you? We go there and we chat,*

it doesn't come out there like you've got dementia at all does it? You seem to be generally living a normal life...Some others have got really bad haven't they? There's a physical difference as well as a mental difference with them, and Francine, well, looks normal doesn't she? (laughter) (Wave One)

As the fieldwork progressed Ron developed the sense that the support group was striving to incorporate new activities to offer a variety of stimulating experiences for younger people with dementia; he noted that Francine had felt proud of her contribution to the collage, and that they had been to the theatre with the group and had been invited to join a singing group. Like Francine, Ron also interpreted the support worker's encouragement for the one-to-one service as incongruous with his perception of her stage of dementia:

Ron: *What you didn't want, in a way it's horrible to say it, but you felt they were pushing for the one-to-one care, when you've actually got to be in the right state of mind to have it, Francine said 'no I don't need it and I'm not going to have it'. You have to be a stage further than that, 'cause it's not the financial thing, we can afford it OK, it's just a mental thing with Francine, she doesn't want it (Wave Two)*

Ron noted that shortly before the third interview, they'd been offered the service again, but acknowledged that the aim of the service is not only to support the person living with dementia, but, considering his own future needs, that:

Ron: *I think, with one-to-one, it's isn't just for the person who's ill, it's also to give the person who would be full-time looking after that person a break (Wave Three)*

Perceptions of mother-in-law's response

From Ron's perspective there seemed to be a slight transition in his mother-in-law's response to Francine's dementia. Over the fieldwork period there seemed to be some fluctuation in the extent to which he perceived that she accepted that Francine had dementia:

Ron: *Her mum should understand more, and she hasn't until recently, she's only just accepted that Francine has got a problem, and that she can't do everything she wants her to do (Wave One)*

***Ron:** I think you also think that your mum doesn't understand that you've got an illness though does she? She doesn't seem to, but she's 82*

(Wave Two)

***Ron:** She has got better. She started saying OK and all that type of stuff. I think it was difficult for that side of the family to accept it. I don't know if they truly believe that Francine has got something wrong with her, but 'cause she's had a lot of bad heads and hasn't felt 100%, that she's starting to realise Francine isn't 100% now*

(Wave Three)

Interestingly it is the '*bad heads*' (Francine's recurrent migraines) that seem to have convinced Joy that Francine has health problems rather than the signs more obviously connected to her dementia, for example, her forgetfulness.

Laurence

Laurence was 36 at the beginning of the data collection period, and was teasingly referred to by David and William as Francine's favourite son. Laurence works as an accountant and is married to Marie and they became parents for the first time shortly after the wave one interview. He often seemed to use the interviews as a means to clarify aspects of his mother's experience, particularly in the first interview. For example, when Francine described forgetting where she had been on holiday, he asked for further details of what she could and could not remember. Although Laurence had appeared to seek information about semantic dementia online, he was sceptical of the content of much of the material, and appeared to perceive Ron as the most informed member of the family.

Motif: Trying to manage his mother's anxiety

A key theme permeating the interviews was Laurence's attempts to reduce his mother's anxiety. When describing his observations of Francine's dementia, he noted that her loss in confidence and need for reassurance were the most apparent manifestations of her condition:

***Laurence:** That's the main thing that I'm seeing is you're less confident, Mum
[**Francine:** I am, yeah] and then you'll often defer to Ron to, for reassurance,*

you know, 'have I said that right, Ron?' [Francine: You've noticed that?] so... you know, that'll probably become more or something, but yeah, don't be afraid to, especially around all your family and friends, don't be...afraid to say something wrong because a) you're probably not, in the first place, and b) nobody cares if you are, so that might help you stay as independent as you can be
(Wave One)

During the third interview a year later, Laurence remarked that Francine rarely said things wrong, and suggested to her that her perception of the frequency of her difficulties was not the same as those around her: '*you probably think you do more than you actually do*' (Wave Three). In trying to reduce Francine's anxiety, Laurence often suggested that her expectations of herself were unrealistic, and sought to normalise memory difficulties:

Laurence: Nobody else would probably think twice, they'd think 'oh God I've, you know, forgotten where I've parked my car, it probably happens to lots of people, but you probably worry more
(Wave One)

For Laurence, Francine's anxiety was caused by a fear of being judged by others. Her desire to please people, he perceives, makes her more vulnerable to fear of making a mistake:

Laurence: You're talking about buying people things, and decision-making, so it's probably because you always wanted to please...you've probably focussed on that a lot over the years, and then that means why you're probably more worried than other people might be about you know, getting something wrong, whereas you shouldn't worry
(Wave One)

For Laurence, every person's memory was limited '*you've only got so much room in your brain*' (Wave One), and it was unrealistic for anyone to expect to remember every person they'd met. In the context of Francine's dementia, when she expressed worries that she struggled to remember former colleagues, Laurence asserted that it was normal to not remember the names of acquaintances:

Laurence: But also, Mum, you've got to remember, you were working [Francine: I can't remember where I worked with them] in retail... in that same place for a heck of a long time, so there would be people that would know you, recognise you, but you might recognise and say hello, but you wouldn't have been their friends
(Wave One)

Laurence also attempted to keep his mother focussed on her remaining abilities in the present, rather than being anxious about the skills that she might lose in the future. He was keen to allay her fears that his inheritance from her mother might be given to his aunts should Francine die before her mother.

He also observed that Francine tended to attribute any physical health problems to her dementia, and encouraged her to be more proactive about seeking medical help for problems such as shaking:

***Laurence:** Have you spoken to the doctor about that (shaking)? Have you mentioned that to the doctor though? [**Francine:** No] Well, why not? You know, what would you be saying if, what would you say to your mum, if that was her?*
(Wave Two)

Motif: Looking for the positives

In addition to Laurence's attempts to normalise memory loss, and to reassure his mother about the limited frequency of her use of the wrong words, he sought to maintain a positive outlook. He encouraged Francine to engage with the varied activities provided by the support group, such as the drawing group: *'it's not a question of whether you're good at it, or not... it's whether you enjoy doing it or not. Have a go and you might like it'* (Wave Two), and to continue to go on holidays. He reflected on his dismay at his mother's initial response to the diagnosis:

***Laurence:** What you were saying early on, when you first had it, you were kind of like 'oh well', you know, 'that's kind of it then' and I didn't... I didn't want you to be kind of giving up or anything. I want you to carry on as normal as long as you can really*
(Wave One)

A year later, in the final interview, Laurence took the opportunity to approve of his mother's decision to carry on with life through engaging with the support groups:

***Laurence:** I guess it's accepting the help... you know, my mum probably could've said 'well OK then I'm just gonna sit in every day, but I'm not going to go to the (support group), I'm not going to go and see people... I'm just going to shut myself away', but [**Ron:** Be positive and carry on life] carry on and do that, accept as much help as you want*
(Wave Three)

Laurence expressed initial upset about his mother's dementia, and felt that there was a lack of justice that she should develop the condition when she had already experienced a lot of ill-health, had raised three children following a difficult relationship with his biological father, and had worked hard all her life:

Laurence: *I always think, over life, things must kind of, you know, balance out, it's only sort of fair, but Mum's, for as long as I can remember, been ill... I remember thinking, you know, it's just not fair* (Wave One)

For Laurence, an important coping mechanism was to try to look for positive outcomes to her dementia. In the first and final interviews, he described how he had become '*less selfish*', and that the importance of family had become more apparent in his life. This affected the way he considered time in relation to family lives:

Laurence: *I get so busy with what I'm doing, that sometimes, you know... we only live 25 miles away, it's not very far, but you know I would probably go a week without even thinking 'oh sugar, I'd better phone'... a week'd easily go by within the blink of an eye and I wouldn't have thought 'oh, Mum, OK, what's she been up to?'* (Wave One)

Laurence also referred in the final interview to the importance of staying connected with family, and not letting months go by without seeing family members: '*it does bring you closer, I guess*'. Between the second and third interview, he and David's family had gone on holiday together for the first time, something, he stated that they probably wouldn't have done if his family hadn't been affected by dementia. In addition, he felt that Francine and Ron would spend more time together, contrasting that with lifecourse norms and that the greater connectedness was the positive outcome of her dementia:

Laurence: *That's probably how I ended up turning it round in my own head was to think...I suspect that what will happen, and probably already is, in a weird way, my mum and Ron will probably end up doing a lot more stuff...than they would otherwise have done so that was the good... 'cause otherwise, I know what would happen...Ron would have worked till he was sort of 65 and they'd have carried on working, you know, for that day when 'oh we can then relax, we can then relax' and you know what happens is you're too old to do anything about it* (Wave One)

For Laurence, then, Francine's dementia seems to have had a positive effect on his construction of family and his conception of time and how time can best be spent.

However, he did express the view that not everyone in the family was affected by Francine's dementia. For example, he perceived that her grandchildren and her mother would be unlikely to notice anything different about her. In addition, he believed that Francine's mother did not really understand the impact of Francine's dementia:

Laurence: *She probably doesn't really (understand) that's because, and I think you probably get worse as you get older, I think you get more and more selfish... you know, she probably thinks 'oh well, I've got worse than Francine' you know [Francine: Yeah, that's it]... and she's always been a bit like that hasn't she? [Francine: Yeah, she has, yeah, that's it]... she probably doesn't kind of (understand) completely because she's selfish (Wave Two)*

Laurence also expressed his admiration for Ron's ability to cope, stating that he had been concerned about Ron but that he was '*doing brilliant*' (Wave One), while Ron felt that he would be able to cope when Francine deteriorated: '*I'm sure I will, because I shall have support, from the family, and because, you want to*' (Wave Two).

David

David was 34 years old at the beginning of the fieldwork period. He is married to Cassandra with two children under the age of 10, Jamie, and Eva. He works in a manual job and lives a few miles away from Francine and Ron.

Motif: 'Everyone does that'

Like Laurence, David sought throughout all the interviews to reduce his mother's anxiety about her dementia, primarily by normalising the difficulties she experienced with her memory and physical dexterity. He perceived that his mother mistakenly attributed problems to her dementia and underestimated the extent to which other people experienced similar difficulties, and demonstrated concern that she tried:

David: *To blame everything on dementia all the time, because everybody makes mistakes, everybody does things wrong, you might just be like, 'cause*

I'm clumsy, you know... you might just be clumsy...I'm clumsy at work a lot of the time... I miss the chisel and hit my thumb, that's just an accident...trying to rush, and that's all it could be
(Wave Two)

With respect to Francine's memory, he felt that, like Laurence, it was unrealistic of her to expect to remember everything '*you got too much to think about, haven't you, you can't just remember everything*' (Wave Three), and, with respect to her forgetting her payment card, described occasions where he too had accidentally left important items at home. When Francine described how she now needed to write a shopping list, he suggested that she hadn't needed to before because she had brought food home after work at the retail store, thus, David demonstrated an earnestness to provide alternative explanations for Francine's experiences, which, to some degree, she seemed to accept:

David: *I think though, you're trying to pinpoint things on dementia which aren't*

Francine: *It's probably true, isn't it?*

David: *Which are some things that everyone gets*
(Wave Two)

However, the extent to which her family members' reassurance helps her is limited. During the same interview, I sought to try and understand whether her family's attempts to reduce her anxiety are effective:

Sue: *Does it help you when people tell you not to worry?*

Francine: *Oh yeah, it does, I try not to, but I can still go to bed and not sleep some nights 'cause I can't get certain things off my head, but I think we all get like that sometimes, don't we? Just sort of everything stresses me*
(Wave Two)

A temporal theme that persisted for David throughout all three interviews is that the level of his mother's anxiety could potentially be related to the speed of the progression of the condition. He frequently stated that he believed worrying would have a deleterious effect on her dementia. In response to her concerns that her brain would continue to reduce in size, David responded by saying '*if you worry more it will, won't it?*' (Wave One). In addition, when Francine described her concerns that she would become like others in the support group, David said:

David: *But Mum, everybody's different, everybody's different in the whole world, and everybody reacts different...they probably went from there, like from your normal (gesturing two points on a trajectory with hands) from there to there quickly, and you might go really slow, and you might not notice it properly till you're about 90... I think if you look more positive and try and not panic, it might actually help and slow it down a bit* (Wave Two)

Motif: Keeping dementia in the background

For David, a key way of reducing her anxiety, and not attributing her difficulties to dementia, was to position her condition in the background of her life. He approved of her decision not to accept the offer of the one-to-one service, feeling that it could reduce her independence: *'if you have it too early, you rely on it, and then you get worse yourself'* (Wave Two). David perceived that making the most of her remaining life needed to be her main priority:

David: *Just try and lead as normal a life for as long as possible, I know it's hard but... if you can, try and forget about it, try and lead your life... try and just look forward to the future...try and not worry because you just need to live your life the best you can* (Wave Two)

Like Laurence, David expressed a desire for Francine not to be concerned about the potential for her mother's money to be inherited by her sisters instead of them, asserting his and his siblings' independence: *'We're big enough and ugly enough to look after ourselves!'* (Wave Three).

Occupying her time well, then, rather than focussing on her dementia, was a key priority for David. He felt that getting the dog had been a positive step, as she now had more confidence to leave the house, whereas before he had felt that she was becoming *'obsessed'* with cleaning and tidying.

Perceptions of family relationships

Similar to other members of the family, David perceived that Francine's mother and her sisters did not understand her condition and were not supportive. He felt that her mother

was jealous of the bond between Francine and her sons and therefore chose to spend more time with Francine's sister. His construction of family, in the context of her dementia, did not seem to include Francine's mum and sisters; when he talked about ensuring Francine did not become isolated, he referred to other family and friends (his wife, his mother-in-law, Marie, Francine's former work colleagues and William's partner) who could visit her and keep her company if she felt lonely rather than Francine's mother or sisters.

While he was unsure whether William's children were aware of Francine's dementia, he perceived that his own children had noticed and remarked on her difficulties:

***David:** I don't know if William has explained it to his kids but Jamie and Eva know something's [Francine: Wrong with me] [William: Natasha and Molly do] 'cause Eva come back and told me that she had to tell Nannie what something was, my mum didn't know, Eva had to tell her, so she come back and told me that 'I had to tell Nannie what this was', it was an animal wasn't it? So Jamie and Eva know*
(Wave Two)

William

Francine's youngest son William was 31 when the study commenced. He works as a security officer and has three children, Natasha, aged 12, Molly, 10 and Cameron, 8, with his partner Melissa. William was present for the first and second interviews but was called into work shortly before I arrived for the third interview. Between the second and third interviews he and Melissa had separated and he was temporarily living with Francine and Ron.

During the interviews William was generally quiet, and when he spoke he tended to echo comments made by his brothers. He did not initiate a discussion unless I asked him a question directly, apart from to describe his eldest daughter's congenital brain problem. In common with his brothers, he tended to normalise Francine's forgetfulness: *'there's been a lot of other employees since then as well, so you're not going to remember all of them, are you?'* (Wave One), *'I forget a lot, to be honest with you'* (Wave Two) and suggested that Francine worried too much over *'trivial things'* (Wave Two).

Like his brothers, William was keen to accentuate Francine and Ron's positive use of time:

William: *They are doing a lot more holidays... doing it now while they're younger. Yeah, like my brother says, about getting the best out of life she can now, while she's young enough and that as well, and like you say, there's a lot of positives that can come out of it... retiring at like 65, 70, like originally and you're too old to do anything, they got time to do that* (Wave One)

He felt that his older children would have some knowledge of their grandmother's condition:

William: *Like Molly, I think she knows as well, but I don't think she'd understand it, but Natasha probably does a little bit, knows a bit about it, I think, 'cause she's quite mature and that, she'll know a little bit* (Wave One)

Like his brothers, William was keen for his mother to remain as independent as possible, and felt that her dog helped to give her more confidence to be out alone and would be able to bring her home if she became disorientated. He also concurred with other family members that she should continue to refuse the offer of the one-to-one service until she needed it.

Marie

Marie was 33 at the time of the first interview, and was present for the first and third interviews. Like William, she tended to be quiet in the interviews, but unlike the others, she did not directly advise Francine to worry less. However, in common with her husband and brothers-in-law, she normalised Francine's difficulties:

Marie: *The more you're thinking about something... I mean, I can be a bit like that, I think a lot of people are (with) decision-making, as soon as you start questioning yourself, I think you do doubt yourself whereas before perhaps you were a bit more confident* (Wave One)

Additionally, when Francine's stress at caring for the grandchildren was remarked upon by Ron, Marie noted that: *'to be fair, for anyone it's quite stressful, isn't it?'* (Wave Three) Comparing Francine's situation at home to her own, being at home with her baby, Francine suggested that they both had too much time to think: *'you get a bit down'* (Wave Three) and that it was important to do something to occupy yourself to improve your

mood. Marie also appeared to be sensitive to the other stresses in Francine's life, for instance, she commented about Joy's dependence on her when she was ill, and also noted the extra stress as a result of the breakdown of William's relationship and subsequent residence at the house: *'just him being here, just adds to your stress, just generally... just having to see him everyday'* (Wave Three).

Marie was keen to encourage and support Francine, remarking on the success of the exhibition of art work in the museum. Additionally, she poignantly described her perception of Francine's dementia in the context of the family, describing the family as a loving, safe haven where signs of her dementia were inconsequential:

Marie: *I hope I'm not speaking out of turns, but I mean, you know, all the grandchildren and all your, you know, children and us, I mean me and Cassandra (David's wife), we love you anyway [Francine: Oh, I know] so it doesn't matter if you say things wrong and you should feel comfortable [Francine: Yeah] in your family 'cause we don't care* (Wave Three)

Marie was also eager to ensure that Francine did not become isolated: *'We all care about you so we're not going to let that happen'* (Wave Three).

Summary

Within Family Three there appeared to be fewer transitions over the course of the fieldwork than in Families One and Two. The ways in which Francine's sons tried to reduce her anxiety by normalising the difficulties she had, and telling her not to worry, continued over the year. While conducted with the best of intentions, it is possible that these communicative practices de-legitimised Francine's experience; she noted herself, with some frustration, that her mother also told her how she was troubled with memory loss. Thus across the generational relationships there was a practice of telling Francine that 'everybody forgets things' which potentially compounded the processes of constructing normality and difference that she was engaged in.

This practice, while common to both her sons and her mother, seemed to reinforce existing relational boundaries; Francine's sons and daughter-in-law were seen as 'belonging' to the experience of dementia, while her mother was not. In a similar way to

Family Two, existing conflicts generated and sustained over years of entwined biographies created the context for the relational practices around dementia, and the diagnosis did not seem to prompt changes to those practices but merely created a different arena for the experience of tensions. For example, Francine's worry about dying prematurely as a result of her dementia caused her to doubt whether her mother and sisters would honour previous agreements regarding her sons' inheritance.

Family Three, like the other families in the study, were striving to reconcile the person they had known for many years with the person becoming affected by dementia (Purves, 2010). They sought to maintain Francine's independence, and seemed to perceive the offer of the one-to-one service as an unwelcome indication from the official sphere that Francine's condition warranted more support. They constructed the family as a safe haven, where the effects of her dementia were irrelevant to the ongoing family practices established over their lifetimes together and seemed, with the exception of Ron, to be reluctant to engage in activities which confirmed the presence of dementia in their lives, such as attending support groups. Participating in research interviews stimulated the discussion of topics which previously had not been addressed within the family, and their participation in the study therefore played a important role in the family's meaning-making processes.

Chapter Nine: Families Four And Five

Only one interview was completed with the final two families in the sample. Sample attrition is a well-recognised problem in longitudinal research (Farrall et al., 2016), and, while some researchers are extremely persistent in their efforts to re-establish contact, for example making over twenty attempts to locate a participant (Leibrich, 1994), in a study with vulnerable adults it is imperative to balance the academic desire for sample retention with the ethical code of treating those whose decision-making capabilities may be affected by their condition with dignity and respect.

While it is disappointing not to have retained all of the original sample, it is understandable that participants may feel that they do not wish to continue to focus on dementia, and for the condition not to be a core aspect of their or their family's identity. In addition, committing to research for a year when a progressive condition has an unknown trajectory is likely to be daunting. As Paterson (2001) noted in her description of the Shifting Perspectives Model of chronic illness, for many there is a desire to disengage from and externalise the illness, locating it in the background of their lives, and for the final two families in the study it is possible that remaining part of the research would have served the unwanted purpose of positioning dementia in the foreground of their lives. Alternatively the initial motivation to participate may have been satisfied during the first interview, or, perhaps particularly in the case of Family Five, stressful circumstances may have created a barrier to continued participation.

FAMILY FOUR

Table 6: Family Four Participants

Generation	Participants Interviewed together	Family members/ friends not interviewed
	Aug 2014	
Generation where one person has young onset dementia	<i>Derek, living with alcohol- related dementia</i>	Derek's brother
Adult children	<i>Annie, daughter</i>	Keith, Annie's partner
Grandchildren		Max, 8 years old

At the time of the interview Derek had just had his 65th birthday. He had been diagnosed with alcohol-related dementia, sometimes referred to as Korsakoff's Syndrome, at the age of 60. His daughter Annie, 36, is his only child. Annie, her partner Keith and their young son Max, 8, sold their flat and moved into Derek's house when it became apparent that Derek could no longer continue to live alone. Derek has a brother who lives over 40 miles away and who he rarely sees and a step-brother and in-laws who they '*never really got on well with*' (**Annie**) and who '*should not be mentioned*' (**Annie**).

Annie

Annie described the events leading up to Derek's diagnosis. Following the unexpected death of his wife during surgery, Derek began to drink heavily, and several months later Annie noticed him looking for his work shoes, although he had been unemployed for some time. A few days later, she was Hoovering, and described what happened as follows:

***Annie:** And he went 'oh are you hoovering up 'cause your mum's coming home?' and I told him 'what do you mean, Mum's died?' and he broke down in tears as if it was the first time and he was telling me that I'm horrible, I'm*

wrong for saying such a thing, and then he locked himself in the downstairs bathroom

Annie managed to get help for Derek quite quickly, but, as a result of needing proof of his dementia because of legal proceedings following her mother's death, they had to travel 'around the country' having appointments with a range of medical specialists. Initially doctors suspected Derek had developed Lewy body dementia but eventually agreed on a diagnosis of Korsakoff's syndrome. Because of her work in care homes, often looking after people in the later stages of dementia, Annie found it difficult to accept the diagnosis, and 'was obsessed that he was having a mental breakdown rather than the dementia'. However, she expressed relief that he did not have Lewy body dementia:

Annie: *Obviously working in care, I know what Lewy body leads to, and I was like, that's all I had in my head, that it was Lewy body. I was kind of relieved when I got told it was Korsakoff's, as bad as that sounds. Lewy body is just awful*

Initially Annie found it difficult to get help for Derek because he was below 65 years of age. She noted that she didn't have support 'for absolutely ages', and found the eventual contact with the local young dementia charity to be a 'godsend'. Derek sees a one-to-one support worker every week, and Annie has contact when required with the charity's family support worker. Through the charity, Annie has been able to arrange respite care at a specialist Korsakoff's syndrome care home and has made arrangements for Derek to attend the day care service in the village centre twice a week. Although she feels that the activities provided at the day centre are more suitable for older people, she remarked that Derek's increasing participation in sociable activities had made him less isolated:

Annie: *He's out of the house three days a week, so that's been going on and that's built him up, 'cause before, when he had no contact really, he was very withdrawn and just sat there watching TV, just constantly, just... but since he's been having more human contact, he's picked up a bit.*

The increased contact perhaps went some way to replace the friendships he had had before his diagnosis. According to Annie, Derek's previous social contact had been drinking and watching football in bars with his friends, and noted that 'all of his friends have just disappeared'. In addition, expanding his activities to include the day centre twice a week meant that he relied less on his one-to-one support worker:

Annie: *Before, it was very much... when's Susanna coming? It's Tuesday she comes, isn't it? And it's like 'yes, Dad' like saying 'you've still got another week' or whatever, he doesn't remember that he went out with her yesterday... but now he's going to the day centre... he's not so fixated on going out with Susanna, it's more spread about a bit now*

Filling the time, and having a structure to the week, then, seemed to improve the family's life, and Annie's aim was to facilitate Derek to *'live his life as much as he can while he can'*. Both the future and the present held uncertainties for Annie. She remarked that she had sought information about Korsakoff's syndrome, and noted that *'there's not even that much research'*. Her understanding was that his condition should not deteriorate if he continues to abstain from alcohol, although *'remembering he's not allowed to drink is an issue as well'*. As far as the present was concerned, Annie noted that Derek had good days and bad days, and that his memory could vary dramatically from being virtually intact to being very poor, and his moods could fluctuate from apathetic to motivated. Living with this uncertainty could be challenging for Annie:

Annie: *it's the not knowing what the next day's gonna bring really which is kind of an issue*

Another aspect of uncertainty was how much independence Derek could have. He walked back from the village centre and went to the local shop alone, but Annie was concerned about the prospect of him catching a bus or train, fearing that he would get lost. In the local environment, Annie felt that enough people knew him in the village and would help him out if he became confused; indeed, she reported that local people would contact her if he was spotted at the cemetery:

Annie: *A lot of people don't realise he's got it, 'cause he's young. Everyone... well the majority of people round the village knows that he has, so, like, if they see Dad up the graveyard, for instance, that's a major one, I'll get a phone call from someone normally saying 'your dad's up by your mum'*

Within the home, Annie's general view was that *'we get on alright round here...all muck in and do stuff'* and that they *'kind of just get on with it, kind of had to'*. Annie's son Max was aware of his granddad's dementia, but stated that he was *'pretty good with it'*, although he did experience some frustration:

Annie: *He knows Granddad's got memory problems, yeah, Max can get frustrated at times, especially when Dad'll turn round and say 'alright if you do what your mum says and get your pyjamas on I'll come up and read you a story, I don't mind' and then Dad'll forget and wander off and Max can get upset about that*

In general Annie seemed to feel that there was sufficient support for Derek in terms of the amount of time he could socialise outside the house. However, she felt that the nature of the activities was often not appropriate and should be more related to the generation of the person with dementia. She felt that Derek was still physically active, and needed pastimes that were more energetic than playing cards and dominoes in the day centre. Playing golf, or going for days out, Annie felt, would be more stimulating. Dementia care in general, she argued, should be individualised:

Annie: *For them not to lose themselves... 'cause you see that happen quite often with the older generation, they get kind of moulded into this is what they're doing, because they can't remember what they did before*

Personally, Annie was a supporter of voluntary euthanasia, and felt that, if diagnosed herself, she would take that option:

Annie: *'Cause I wouldn't want my family to go through it. 'Cause it's never the person that's got the dementia that is bothered it's the family around them*

Derek

During the interview Derek was generally quiet, and was much more animated when engaged on subjects other than his dementia. Humour seemed to be important to Derek, and he occasionally teased Annie, telling her laughingly that she could '*shoot him*' if he became too much of a burden. The affection between them was apparent; at one point he said '*bless her, she knows I love her to bits*'. Although he didn't discuss the challenges of his dementia, he described the support services that he had, and suggested that while the day centre was quite enjoyable, the entertainment lacked imagination:

Derek: *There's not a lot of thought goes into that, is there?*

In contrast, he seemed to appreciate the one-to-one service with the dementia charity support worker. He confirmed that they had a good relationship, and that being with someone of the same generation who had similar interests was important. He described how they went to cafes, museums, cinemas and walks, and stated that, in contrast, there was little point sitting at the day centre reading newspapers, when '*you can do that here, can't you?*' He viewed communication between caregivers and people with dementia as crucial:

Derek: *Communication should be the utmost, should be paramount, shouldn't it?*

Attending respite care at the Korsakoff's care home also seemed to be enjoyable for Derek, with a range of activities such as day trips and good staff, facilities and entertainments such as mini-golf and bingo. Although many of the residents were older than him, he felt there were a range of suitable activities for him to engage in.

FAMILY FIVE

Table 7: Family Five Participants

Generation	Participants Interviewed together	Family members/ friends not interviewed
	Aug 2014	
Generation where one person has young onset dementia	Doreen , <i>Craig's mother</i>	Joan , <i>living with Alzheimer's Disease</i>
Adult children	Cheryl , <i>Joan's daughter</i> Craig , <i>her spouse</i>	George , <i>Cheryl's brother</i>
Grandchildren		Scott , <i>17 years old</i> Ethan , <i>15 years old</i>

When I arrived at the house I was expecting to interview Joan, a 64 year old person living with Alzheimers' Disease and her daughter Cheryl. However, Cheryl informed me that Joan was not well enough to be interviewed; they had recently returned from holiday and

Joan was reportedly experiencing a greater degree of confusion than usual since the return home. Cheryl's husband Craig was present, along with Craig's mother Doreen. Cheryl and Craig have two teenaged sons, Scott, 17, and Ethan, 15.

Cheryl

39 year old Cheryl is a full-time mother. Several years previously, she had had an accident which had caused a brain injury. Her memory was badly affected, and, while markedly improved, can occasionally be unreliable. This is relevant to her account as she referred to her ability to empathise with her mother's memory difficulties; however, she also feels that her emotional response to her mother's Alzheimer's Disease is exacerbated as it causes her to reinterpret her past and her family's experience of looking after her when her memory was badly affected:

***Cheryl:** For me (it) was really hard because when I first had my accident I had no memory at all, so to see it from the other side, and realising what Craig and the boys and Doreen and Mum had been through, I found quite upsetting*

Revisiting the past in the present happened throughout the interview, particularly in respect of trying to reconcile contradictory memories of her mother in the past with her perception of how her mother is now. She referred to her mother's capabilities in the past with admiration:

***Cheryl:** She was the most confident, strongest woman I have ever met, she's been round the world on her own, she's been trekking in Peru, she's been up Mount Vesuvius, you name it she's been there and she's done it... She had an incredibly high-powered job as well... and I think that's what I find the hardest, she was **so** confident, and absolutely fantastic at everything, wasn't she? I mean, she's brought me and my brother up single-handedly, my father was... huh... less than useless. She used to fly off round the world for business and things like that. I can't even get her to step outside of the front door, some days (original emphasis)*

For Cheryl, Joan's age when she developed dementia was a key aspect of the experience. Initially, they were told that Joan had Pick's Disease, which, as they were told the life expectancy was between two and ten years, and at that point Joan had already been displaying symptoms for around five years, was described by Cheryl as a '*devastating*' experience. For Joan to be re-diagnosed as having Alzheimer's Disease was a '*relief*'. A

strong family history of later-onset dementia seemed to have prepared Joan and Cheryl to some extent that dementia might become a part of their future. However, developing the condition at the age of 60 was shocking and not only delayed the path to diagnosis by a few years but also inhibited access to dementia services:

Cheryl: *I mean, we always knew dementia could happen, because there was such a strong family link to it, on her father's side. But never in a million years would I have expected that at 60... 'She's not old enough', that's what I get all the time. 'She's not old enough, she's not over 65' but she's still got it. 'Yes, but she's not over 65, so we can't take her'*

Cheryl's frustration at the lack of support services for Joan extended to the lack of information and advice for her and Craig. They felt that one of their main challenges was making decisions about Joan's future accommodation and care, a challenge that strained their relationship: 'we do fall out about it don't we?' They remarked that her current house was too big and too expensive to maintain, but feared that moving her into a care home with older people would cause her to deteriorate much more quickly. From Cheryl's perspective, there is a lack of support with decision-making:

Cheryl: *Even if someone could say, right, I know it's not as black and white as this, but, these are the symptoms that she's got, this is what's happening, therefore the next step is sheltered accommodation, or it is just a smaller house, or it is a home... And it's what do you do, what is the right thing to do, all of that, they're all decisions that are hard and you have to make them*

Another dilemma for Cheryl was the extent to which she should control her mother's money. Following her mother being defrauded over the telephone for £2000, she and Craig had arranged a Power of Attorney, but wanted to continue to support Joan to retain independence when shopping. However, paying at the checkout was often difficult for Joan, and Cheryl felt that, in general, members of the public lacked understanding, and would often 'stand and giggle', or seem to consider her behaviour 'weird' as they would not expect dementia in someone of her age. At times Joan would be aware of bystanders' reactions, and want to go home:

Cheryl: *Sometimes she's aware of how they react and sometimes she isn't. And when they do, is when she tends to say 'let's go home' or 'I don't want to do this anymore'*

For Cheryl her mother's behaviour in shops could be embarrassing and her own reaction could cause a lasting sense of guilt. One particular incident in a shop was a turning point for Cheryl when she realised the extent to which her mother was affected by dementia:

Cheryl: *There was one time that I took her shopping, and we were getting her some new bras, and all of a sudden she appears in the middle of the shop in her underwear and that was really hard. That I think, was the moment for me that it really hit home, what was happening... the fact that people were giggling and staring I actually lost my temper, but rather than yell at them, for them being, sort of because they didn't understand, I yelled at mum. And that made me feel really bad because I've reacted to something outside of mum that she couldn't control, yet I still took it out on her, and that felt really bad.*

The emotional impact of her mother's dementia seemed particularly difficult to deal with. While she and Craig had devised practical strategies to try and support Joan, such as arranging for carers to give her medication, leaving notes around the house as reminders, buying clocks, calendars and diaries to try and keep her aware of the date and time, and checking her cupboards before going grocery shopping, the awareness of her sorrow deeply affected Cheryl:

Cheryl: *It doesn't bother me when she's happy, but it's when she's sad and you can see the sadness in her eyes, that's the hardest*

Her mother's temporal confusion was also distressing for Cheryl. Thinking that her own mother was still alive, and thinking that her grandsons were younger than they were was described as difficult to cope with. In addition, she and Craig also drew attention to the significant impact of the condition on the relationship between Joan and their sons. Scott and Ethan reportedly had difficulty reconciling their previous and current experiences of interactions with their grandmother:

Cheryl: *The boys are at an age where they've noticed it because she used to have them for one weekend at least every month. They'd go on a Friday night and they'd come back on the Sunday which meant it gave us a break from looking after Liam, and it gave her time with them. She'd take them to the cinema, she'd take them to the zoo, wildlife park, she took Ethan to a train museum, she'd take Scott to Shakespeare plays, 'cause he'd absolutely adore them, she was amazing with them, and they absolutely adored her, and seeing her like this, it's really affected them, hasn't it? [Craig: Umm, they find it difficult]. They both want to see her all the time, like they used to before, and*

for a couple of years Ethan didn't understand, did he? Why they didn't go there anymore. And he found that really hard.

Craig: *Even up till now, as well, he finds it difficult to talk to her, to find*

Cheryl: *'Cause he doesn't know what to say*

Craig: *He doesn't know what to say, or how to cope with the situation that she's forgetting things, and so on and so forth, erm and in some respects it's got to a stage where he's like, 'I don't want to spend time one-to-one with her' because he's too uncomfortable.*

Cheryl: *He wants to, but he doesn't want to*

Craig: *He feels very uncomfortable, because he's not even 16 yet, so coping with it for him is very difficult. He'd rather just say 'I'm going upstairs' or 'I'm going to go and do this' or whatever and*

Cheryl: *He'll disappear*

Craig: *Leave it to the adults*

Cheryl: *Whereas Scott, being autistic, he can overload people with information, he does that an awful lot, and of course when he does that to mum she just stares at him blankly, and he expects an answer because he's always had an answer and she doesn't do it anymore, so I'm constantly having to say to Liam, 'just say the bare minimum, say exactly what you want to say, but don't then go on about it, because she won't understand what you're talking about'*

Their grandmother's dementia has significantly affected the way they interact with their grandmother Joan, but appears to have had less impact on Cheryl's brother George. George lives over 50 miles away, and, from Cheryl's and Doreen's perspectives, is reluctant to accept Joan's condition and is less aware of the effects of the condition on her capabilities:

Cheryl: *My brother is flipping less than useless... He hardly ever sees her. He does phone her, he does phone her most nights, but if something needs doing, it's 'oh, Cheryl'll do it'... so it's always down to me. Because he doesn't see her all the time. She can be very different on a telephone because you can't see her*

Doreen: *And also, I think when he comes down she tries that little bit harder*
[Cheryl: *Yeah, she does]* *when he comes down to see her, doesn't she?*

Cheryl: *Yeah, she does, she does, and I think a lot of it as well with George, is he's trying to pretend it's not happening.*

Doreen: *He sees what he wants to see.*

Cheryl: *He tries to pretend it's not actually happening. Erm, because he's already said that if he gets dementia the age that she is he's going to throw himself off a bridge, which is really not very helpful.*

With the strong family history of dementia, Cheryl reflected on her concerns about developing the condition herself and what it might mean for her sons:

Cheryl: *I mean, potentially at any time that could happen to me. I mean, I've already got enough memory problems and health problems and I really don't want another one but it's scary to think like that as well, so from a completely selfish point of view you do think about yourself, and you think about, oh my God, are my kids gonna have to go through watching me?*

Constructing understandings of dementia through comparing the condition they live with either with other forms of dementia, or with other forms of serious illness, was relatively common amongst participants, and, for Cheryl, even though she acknowledged the serious, debilitating nature of cancer, in some ways she perceived it as preferable to dementia:

Cheryl: *Cancer is terrible, it kills people, and it's a nightmare, but your brain still works. You're still that same person.*

In contrast, she viewed dementia as a condition which alters personalities, and takes away the person that they once were, creating an ambiguity about their selfhood and role within the family:

Cheryl: *And it's like she's dying but she's still there [Doreen: Yeah, yeah] but she's not my mum but she is, but she's not, if you see what I mean. She's not that person that she was, and never in a million years could I have imagined that she'd be the person that she is now [Doreen: No] at her age. Not in a million years.*

Craig

There was a large degree of consensus between Craig's account and Cheryl's. He was very conscious of the need for proximity to Joan, as he was concerned that she needed planned activities. From his perspective, structuring her time was perceived as an important way of improving her state of mind:

Craig: *It's like a structure, routine isn't it. If we've got things in place, if we've got like Monday, she's doing this, Tuesday she's got young dementia, Wednesday, it's that, if her week's planned out and she's got things she knows are coming up, because she's got a diary, she'll look into it, then she's a lot calmer, but if there's a week coming up when there's nothing on, you can guarantee that week, carers'll come in, wake her up, and if she's got nothing on, she'll just go back to bed and that's it... I think in some respects it makes her day go quicker if she's in bed sleeping, rather than downstairs on her own, nothing to do*

Motivating Joan to be more active could be challenging, but seemed to have a therapeutic effect:

Craig: *You do have to force her to do it... but if you get her up and you motivate her, and say, she's got this to do, she's got that to do, then she's a lot better and especially in the afternoons and evenings*

Although Cheryl was slightly concerned about Joan's newly-discovered sweet tooth, and excessive consumption of biscuits, for Craig, the biscuits had become part of her routine, something for her to do when she was on her own at home 'to try and keep the afternoon going'. His mother Doreen concurred that routines and habits are helpful when you live alone, creating a sense of security and stability:

Doreen: *That is routine in that respect because I live on my own and I do that...you get into your routine and you think, right, and I'll sit there and I'll either get my book or... I've always got a packet of crisps or a packet of biscuits ... it's a comfort, routine, in a sense, that that's what you do and you know that's what you do*

Their concerns about what Joan would be doing on her own if they were unable to visit were apparent. When Joan had no activities planned, Craig felt that it became a vicious circle, in that her mood would become low and she would feel apathetic. While Craig and

Cheryl were aware how much Joan enjoyed her weekly visits from her dementia charity one-to-one support worker, 'who she **absolutely** adores' [**Cheryl**, original emphasis] Craig felt that a day centre where Joan could socialise frequently with others of a similar age would be useful:

***Craig:** There's nothing in the area for her...I think there should be somewhere where they could at least go and socialise or go to rather than just being left as such. If we're busy and we can't go over and see her or whatever she's got to cope with that on her own for the rest of the day, you know, not very nice.*

Craig was conscious that dementia was starting to have a higher profile nationally, and was more visible in the media, but that current research is focussed on finding a cure, or preventing dementia, rather than focussing on helping people who are already living with the condition. From Craig's perspective, they were experiencing a lot of stress in the present and that there was likely to be a gradual accumulation of strain:

***Craig:** It's just one thing now after another after another and as it gets worse and worse and worse, it'll be more and more and more*

Doreen

Doreen lived over 50 miles away and stated that she usually saw Joan two or three times a year. Her account was largely consistent with Cheryl and Craig's, although she perceived herself to have a different perspective on the ways in which Joan's dementia affected her son and daughter-in-law:

***Doreen:** This is what I'm saying, and this is the bit that worries me, because as... I won't say as an outsider looking in, [**Cheryl:** Yeah] but strictly like that, as an outsider looking in, I can see it from a different angle to how you two see it, and all I see is you two getting very very stressed out, you in particular, Cheryl, you worry me to death sometimes, especially when I'm on the phone to you 'cause I'm so far away I can't do anything, which, alright, it puts stress on me to a degree but nothing like on you, I stress for a different reason to what you do*

Doreen had been on the recent family holiday, and had observed a marked decline in Joan's capabilities; for instance crossing the road safely and being aware of the pain caused by her sunburn. Doreen became more involved in Joan's personal care whilst on

holiday, helping with cutting her toenails, changing dressings and, on occasion, taking her to the toilet. She observed that Joan perceived herself as a cause of strain within the family:

Doreen: *She'll apologise before she'll apologise. Yeah, she'll say 'oh I'm sorry I'm a nuisance' or 'I'm sorry I'm being such a bother'. You'll say, 'well, no, you're not' she'll say 'well, I feel as if I am' but she doesn't know what she's being sorry for. [Cheryl: If you asked her, she wouldn't know] She just says 'I'm sorry, I don't mean to be a trouble' and she won't tell you things because she doesn't want to be a problem, does she?*

Doreen was also very aware of bystanders' reactions in public places, and the lack of understanding shown by the general public. For Doreen, the reactions were related to Joan's age:

Doreen: *With somebody younger, people ... I don't know what it is, it's the thing isn't it, that they look at you and it's 'well, she should know better'*
[Cheryl: *Yeah] and that's the, that's the bit that annoys you because they sort of look at you as if to say 'she should know better, what's she doing that for?'*
[Cheryl: *That's really hard] because she's younger, they don't even associate that there's anything, anything wrong and that's very hard, that is*

Doreen's reaction to the effect of Joan's dementia on the family was shaped by the experience of Cheryl's accident. Craig remarked that he had struggled to obtain support for a long time after Cheryl's accident and only received help when he became very distressed during a GP appointment. For Doreen, Craig and Cheryl needed to be able to have reliable access to support to prevent them developing mental health problems:

Doreen: *But you shouldn't have to get to that stage before they decide to do something. But I know you went through years and years of it driving everybody mad in a sense because we couldn't get any answers. He couldn't get any answers, he couldn't do anything, and they just passed you from one to the other till it got to that stage where you'd had enough, and this is what worries me now is ...you're both going to get to that situation again where you think 'what do we do now?' and it builds up and it builds up and you both fall apart. What good is that to anybody? That doesn't help you and it certainly doesn't help Joan [Cheryl: No]. It doesn't help me, and it doesn't help your boys, but you've got nobody to turn to... this is gonna sound awful, but it's you two that's gonna crack, before your mum does... and that's the bit that worries me, because if you two end up with nervous breakdowns, or whatever, who's*

going to look after you two? And you know, you know I will be here, you know that, you don't have to ask that question, but that is the point I'm putting, there is nobody to give you help

Conducting research with a family experiencing such stress created an ethical responsibility. Following the interview, I encouraged Cheryl to contact the family support worker at the dementia charity to try and access some additional support to help with the challenges they were facing. I also informed her about the Admiral Nurse service, of which she had no prior knowledge.

Reflections on cross-sectional and longitudinal methods

While it was disappointing that Family Four and Family Five were not retained throughout the duration of the study, it does provide an opportunity to reflect on the relative value of the cross-sectional and longitudinal methods in developing understandings of the experience of living with young onset dementia.

In both interviews there were experiences that it would have been useful to develop understandings of over time. For example, in Family Four, I would have sought to gain more insights into Derek's perspective; it is possible that repeated contact might have established a degree of trust where he might have become more open in discussing his experiences of dementia. There were hints that he felt he could have more independence, for example, when Annie stated that she was afraid of him becoming confused using public transport, he said '*don't be*'. In Family One, Jack, Louise's husband, was very talkative in the first interview, but only to reiterate his wife's account, only starting to reveal his unique perspective during the second and third interviews. A similar experience may have happened with Derek if he and Annie had continued their participation in the study.

Annie presented herself as a capable, resourceful and self-assured person, and it would have been interesting to develop a greater sense over time of her sources of support, and further insights into how she felt Derek's dementia affected relationships within the family. Smart (2007) has noted that families often display a reluctance to discuss the negative aspects of their relationships. While this was not my experience with Families

Two and Five, in Family Three Francine revealed more about her problematic relationships with her mother and sisters and Ron described the troubled relationship with his son in the final interview. If Family Four had continued their involvement with the study, more may have come to light about the family that *'should not be mentioned'* and the interplay between the relational difficulties and Derek's dementia.

Family Five were clearly living in very distressing circumstances, with Cheryl and Craig in a position of having to make momentous decisions about Joan's future. Given the circumstances they were in, it is understandable that, while they had appreciated taking part in the first interview, that there were probably too many demands on their time for them to be able to continue their involvement. From a research perspective, it would have been useful to have observed the family over time to see how they dealt with the challenges of making the decisions, and in what ways the support from the dementia charity may have helped them. I would also have attempted to interview Joan and Cheryl's sons Scott and Ethan if the family had continued their participation in the study.

Chapter Ten: Discussion

Introduction

I argue that this thesis has generated original knowledge through the use of an overarching symbolic interactionist perspective and a qualitative longitudinal methodology which encourages exploration of meaning-making processes through the interweaving of biographical, historical and generational time. This approach, unique within the young onset dementia body of knowledge, enables novel insights into the effects of the condition on different generations over time. Moreover, theorising using family practices, the sociology of personal life and belonging as conceptual aides draws attention to relationality rather than focussing on the identity of the ill person, a theoretical stance commonly found in the sociology of chronic illness body of knowledge. The virtual absence of intergenerational studies within the young onset dementia literature impoverishes the field, and this thesis, therefore, offers new, much-needed understandings of the processes that occur within and across generations where one person has young onset dementia. Through moving away from individual perspectives, or the carer-cared for dyad, which frames much of the research on the subjective experience of dementia, I have provided a more holistic perspective on the complex and subtle ways in which the emergence of the condition affects interconnected personal relationships.

Overall what has emerged through this thesis are complex and compelling pictures of living with young onset dementia. Within a family group, some members 'belong' to the experience of dementia and some do not, mediated through family practices and largely contingent upon the nature of the existing relationships before the emergence of the condition, or, in the case of grandchildren, upon the perceptions of maturity and ability to be aware of change. There is no evidence within the data set that dementia has a healing influence on troubled relationships; rather, the condition appears to become another conduit for the expression of existing tensions. In contrast, for families who perceive themselves to be supportive and close, the emergence of young onset dementia seemed to augment the existing intimacy, renewing a sense of the importance of shared

family space and time. Thus young onset dementia within these family and friendship networks seems to provide another means through which relationships are reconstituted rather than as a reason to resolve relational conflicts.

The families in this study were striving to make sense of young onset dementia over time, and this process is multi-faceted, as individuals socially negotiate meanings through various interrelated phenomena: self and identity, the responses of family members and friends, the processes by which knowledge is sought and either shared or withheld, perceptions of social expectations and norms, consciousness of the body, and the acute observation of others who are living with young onset dementia. Temporal threads run through the experiences as family and other social practices are conducted in the present, framed by the past, and projected into the future. Thus, focussing on the temporal by employing a QL lens draws us closer to an understanding of an illness which affects families and friendships in profound ways and enables us to explore transitions and continuities as people intersubjectively construct meanings and engage in action on the basis of those meanings.

Using these orientations produces richly contextualised unique knowledge which will be further elucidated within this chapter. Specifically, I argue that the following findings are unique to this thesis: *transgenerationality*, where a grandparent is perceived to have relocated in a grandchild's generation and *constructions of generational belonging to the family/friendships-experiencing-dementia*, comprising *unrealistic parental expectations*, that parents of young people with dementia reportedly lack understanding of the condition and the limitations imposed by it on their children and *assumptions about grandchildren's awareness*, that adult generations generally assume that grandchildren have limited awareness and are therefore only minimally affected by their grandparents' dementia.

Epistemological stance

Prior to providing a discussion of the findings it is appropriate to return to the central epistemological question that underpins the thesis and to explicate the claims to

knowledge that are being made. As stated previously, conceptualising knowledge about families from an objectivist standpoint would entail aiming to generate factual knowledge about family experiences. At the other end of the spectrum, a postmodern relativist stance would generate a multiplicity of individual truths about which no interpretation or analysis could be made. I concur with Jamieson (2011), who suggests that giving marginalised people a voice, as I have attempted to do, is not inconsistent with taking an interpretative stance as long as the researcher is self-reflexive; I have, therefore, attempted to both give authentic accounts from the participants' perspectives while offering interpretations from my own.

In chapters six through to ten, I have taken a vertical look at individual family case studies, exploring how people within those families socially and intergenerationally create meanings of young onset dementia and the kinds of practices they undertake in the context of the condition. The question that arises is, in a small yet diverse sample of families, with differential diagnoses of dementia, is it meaningful to conduct a cross-contextual analysis or is such an endeavour fruitless because the particular uniqueness of the cases defies comparative analysis? Following Irwin (2013), a leading figure in qualitative longitudinal research, I argue that cases should be brought into conversation with one another in order to situate the data and to understand the influences of contextual diversity on embedded relationships in the experience of young onset dementia. Scrutiny of the processes that occur within a particular context is facilitated through comparison, and therefore I have decided, inspired by Brannen, Moss and Mooney (2004) and Thomson (2014b), to further interrogate the data by looking across generations to elicit detailed insights into generational practices. Prior to that, however, it is important to consider the influences of the historical time within which this study has been conducted.

Historical time

Although the families who participated in this study lived within enmeshed intergenerational relationships within their own unique contexts, they were all experiencing young onset dementia at the same moment in time, at a particular point

where dementia was starting to receive much more attention in policy, research and, with the release of *Still Alice* in 2014 (for which leading actress Julianne Moore won an Academy Award), in popular culture. In the years since the release of the National Dementia Strategy (2009), dementia has '*never had such a high profile*' (Alzheimer's Society, 2015, p. v) both nationally and globally. The G8 summit (2013), under UK presidency, ended with a signed declaration outlining international commitment to research, one element of which was creating a mechanism to enable people with dementia to participate in clinical trials. Nationally, the Prime Minister's Challenge on Dementia (2012) created two key initiatives which comprise a country-wide response to dementia; the Dementia Action Alliance, which operates at a national level to influence policy and at local levels to develop collaborative links between organisations, and the Alzheimer Society's Dementia Friends initiative which aims to change public perceptions of dementia through education. The face of the Dementia Friends campaign is Gina Shaw, herself a younger person with dementia, and at the time of writing, over 1.5 million people have become Dementia Friends (source: www.dementiafriends.org.uk).

With much of public discourse pivoting on the maxim 'living well with dementia' (Department of Health, 2009; Dementia Action Alliance website, 2016 <http://www.dementiaaction.org.uk/>; NHS choices website, 2016 <http://www.nhs.uk/Conditions/dementia-guide/Pages/living-well-with-dementia.aspx>), the study participants are moving through a moment in history where substantial efforts are being made to promote positive images of dementia and to challenge stereotypes and stigma. In their meta-study of chronic illness, Thorne et al. (2002) found that discourse had a significant effect on the orientation of researchers, citing a move away from concepts such as burden and stress towards courage and transformation; this, they reasoned, was due to a shift to a more affirming public discourse. Extrapolating their point, it is not unreasonable to suggest that the public initiatives to improve the perception of dementia are likely to have influenced not just myself but also my participants. In particular, in Family One and Family Two, there was an increasing sense of belonging to the dementia social movement as participants became more immersed over the fieldwork period in campaigning, fundraising, research and educational activities. Increased interest and funding has undoubtedly created opportunities for people with

dementia to participate in a wider range of activities, including employment as advocates, facilitators and researchers. Conversely, as people like those in my study use their agency in dementia-related activities, more momentum is created within the social movement.

As the study participants live through this moment in history, they will be influenced both by the increasing socio-political focus on dementia, and also by the act of participating in this research study.

Generational time

Although the term generation has been operationalised in different ways in studies (Thomson, 2014a), in this thesis I have used the term generation to refer to position within a family rather than a historical birth cohort. However, there is little age variation within all but the youngest generation, with parents being octogenarians, the generation diagnosed with young onset dementia late 50s or early 60s, the adult children being in their 30s and the youngest generation aged between 7 and 17. Thomson (2014b), in her intergenerational QL study *'The Making of Modern Motherhood'*, has argued that exploring generations across different family cases enables the creation of '*dense and complex*' accounts (2014a, p. 149) which privilege psychosocial processes. Following her, and other researchers' lead (Brannen et al., 2004; May & Muir, 2015), I have opted to '*slice*' (Neale, 2015, p. 26) the data into generational strata to explore whether illness experiences differ for people within different generations. Therefore, this chapter considers cross-case generational perspectives. For ease of reading, 'Family One' has been contracted to 'F1' and 'Family Two' to 'F2' and so forth.

Generational perspectives

The oldest generation: Parents of people with young onset dementia

There were three living parents in two of the longitudinal families of people with young onset dementia: mother Violet and father Jonathan (F2) and mother Joy (F3). None of the parents took part in interviews, therefore the understandings constructed are partial and based on the proxy reports of other family members. Julia (F2) had arranged for her parents to attend the third interview, but unfortunately they, from her perspective, made an 'excuse' not to participate during a telephone conversation just before they were due to be collected. Julia and Peter both appeared to be very disappointed by her parents non-attendance, although Peter felt he knew the reason:

Peter: *'Cause all they'd be worrying about... I can see them now, I can read their minds, [Eliza: They wouldn't talk, they wouldn't talk, would they?] all they'd be worried about would be who'd be here, 'cause they think that maybe Colin and Celeste were here. I think they're a bit jealous 'cause they do so much for us, Colin and Celeste, you see. And her mother was always a control freak and now everything's been took out of her hands, you know, she can't rule the roost if you know what I mean*
(Wave Three)

Likewise, Francine's mother Joy (F3) had been asked to participate but had chosen not to. Using the lens of family practices, none of the three parents appeared to act in ways to associate themselves with their daughters' dementia, and did not seem to belong to the sets of relationships that experienced dementia. All three parents, as understood through the proxy accounts of other participants, did not appear to fully acknowledge the effects of the condition on their daughters.

It would appear that Violet uses the schema developed during her mother's experience of dementia in the past to guide her actions in the present; the suggestion that she sees dementia as a family secret and is discomfited at the thought of others beyond the family knowing suggests a lack of congruence between the symbolic family she wishes to display socially (Finch, 2007), and the lived experience of having a daughter with dementia. As

the fieldwork progressed, Julia actively chose to distance herself from her parents, but inviting them to the interview suggests a desire for them to participate in and have greater knowledge of her experience. Additionally, although the offer was rejected, Violet had asked Julia if they could look after her when she was having a bad day. Therefore there is a complex relational picture emerging, possibly underpinned by notions of moral duty towards one's family. Invitations are extended but are rebuffed, and the boundary surrounding the family/friendships-experiencing-dementia temporarily becomes permeable but then is reconstituted.

Likewise, in F3, Joy did not appear to belong to the family/friendships-experiencing-dementia. Reportedly she was more enmeshed in the lives of Francine's sisters, and, from the proxy accounts, appeared to lack understanding of the effect of dementia on Francine's capabilities. The issue of possible jealousy was also mentioned in this family as middle son David suggested that Joy may envy the closeness of the relationships between Francine, Ron and the sons, although older brother Laurence disagreed, interpreting Joy's actions as resulting from selfishness. For Francine, her mother's perceived favouritism of the younger sister whom Francine did not communicate with, created a barrier between them, and according to Ron, Joy only began to appreciate Francine's ill-health because of physical symptoms rather than her signs of cognitive decline.

All three parents, in different ways, seemed to de-legitimise Francine's and Julia's experience of young onset dementia, and through their practices appeared to be excluded, or to consciously or unconsciously exclude themselves, from the family/friendships-experiencing-dementia. The issue of jealousy was raised by both families, and it is possible that the parents' perception of close, cohesive relationships within sets of relationships within the family and/or friendship group may have created a sense of being excluded.

Having a child with dementia may also destabilise notions of anticipated care; this was stated clearly by Julia's parents whose primary concern, when informed of her diagnosis, apparently was to be concerned about who would look after them in future. Francine had already supported Joy through a health crisis, reportedly having more input into her care

than either of her sisters, something which seemed to cause resentment. Any future health care needs Joy might experience may not be able to be provided by Francine as her own condition deteriorates.

As there is currently no research evidence on parents in the young onset dementia literature, this evidence cannot be contextualised within an existing knowledge base. However, Jowsey et al. (2013) in their work on chronic illness experiences have suggested that socially negotiated meanings of chronic illness are embedded in family history. Violet's experience of dementia in an earlier generation, and the secrecy that reportedly surrounded it, is likely to have been highly influential on both her and Julia's meaning-making processes.

The generation within which participants were diagnosed with young onset dementia

Nine participants gave accounts within this generational stratum: Louise, Jack and Josie (F1), Julia and Peter (F2), Ron and Francine (F3), Derek (F4) and Doreen (F5). In addition, significant other people from this generation who were discussed in interviews were brother Phillip and friends Colin and Celeste (F2), Francine's sisters (F3) and Joan, living with Alzheimer's disease (F5).

Making sense of young onset dementia

Normalisation is a well-recognised phenomenon in the sociology of chronic illness (Knafl & Gilliss, 2002; Bray et al., 2014) and was also identified by Forrest Keenan et al. (2007) in their study of children of parents with Huntington's Disease. While Monaghan and Gabe (2015) found that normalisation was contingent on perceived or anticipated reactions of others, in this study participants tended to contextualise dementia and normality through the use of comparison, either to other people with dementia, people with other forms of illness, or, in the case of Louise, with neighbours who were perceived to be 'abnormal' because of their engagement in anti-social behaviour. Interestingly, with the exception of

Doreen, none of the participants in this generation highlighted the young age of onset as a key aspect of their experience. Thus there is limited evidence within this generation to support the notion of the '*social clock*' of illness (Bury & Holme, 1991) or the sense of ageing prematurely noted by Clemerson et al. (2014).

Participation in support groups seemed to be a key factor in constructing a sense of normality by two processes. Firstly, comparing the experience of their condition favourably to others at support groups, particularly those who they perceived to be '*quite far down the road*' (Peter, F2) enabled some of the participants to establish a sense of themselves as normal, and, secondly, socialising with others experiencing similar difficulties created a new sense of normality. Belonging to the groups seemed to be a hugely significant factor affecting the ways in which people constructed their dementia; significant friendships seemed to be quickly formed, previously referred to as accelerated intimacy. The formation of friendships, and the opportunity to relax and socialise without fear of embarrassing instances of memory loss gave the participants a 'normal' space. This corroborates the findings of Pipon-Young et al. (2012), who noted that their participants developed a shared identity in a young onset dementia support group. However, witnessing people in the later stages of dementia potentially foreshadowed the participants' futures.

The social experience of dementia seemed far more pertinent to participants in their meaning-making processes than hospital care. In general, people with dementia tended to view their routine hospital visits as little more than a means of tracking the rate of their deterioration. However, appointments where the diagnosis was received were particularly shocking; for Francine, the image of her shrunken left hemisphere was a turning point: her dementia became undeniable as the invisible became visible. For Julia, who, after months of appointments, was expecting to be diagnosed with an eye problem, learning that she had dementia was extremely distressing. For Louise too, diagnosis, and the identity transition from a physically fit, effortlessly multi-tasking person to someone with dementia was shocking, and one which she seemed to recompense for over time by making herself physically fitter. Thus all these participants experienced diagnosis as a '*fateful moment*' (Giddens, 1991, p. 202) which required them to '*rethink fundamental*

aspects of [their] existence and future projects' (p. 202/203). Difficult diagnosis experiences are commonly described in the young onset dementia literature (e.g. Beattie et al., 2004; Clemerson et al., 2014) and this study provides further evidence of that phenomenon.

The impact of the dementia on their working lives was particularly pertinent to Louise, Julia and Francine. Louise suggested that she would have construed her memory loss as age-related if she had been retired. In a similar way to some of Harris and Keady's (2009) and Johannessen and Möller's (2011) participants, Francine's inability to either perform routine tasks or to learn new ones was dismaying in the context of her identity as a competent manager, and for Julia, there was a moral issue of feeling undeserving of the money she earned. The dissonance experienced within their identity as competent employees disrupted their sense of belonging to their particular working role and to the workforce in general. Thus there is evidence that participants experienced biographical disruption (Bury, 1982) as a result of their diagnosis, and had to reconfigure their sense of self as a result of their dementia.

Other family members in this generation drew attention to the invisibility of dementia in comparison to other illnesses, such as blindness or disability. Ron (F3), for example, remarked that:

Ron: *People with dementia, they haven't got a sign saying that have they, so you know, it's difficult...it's more difficult when there's something you don't know, isn't it?*
(Wave Two)

For Doreen (F5), the invisibility of dementia was compounded by the age of onset, and expressed the view that people in public spaces would not assume Joan's behaviour would be caused by dementia. The fluctuating visibility of young onset dementia may be harder to contend with than either permanently visible or invisible conditions (Joachim and Acorn, 2000), and those who have a personal relationship with people with dementia may experience associative stigma (Catthoor et al., 2015).

Several of the participants in this generation described their understanding of the cause of dementia. Interestingly, even for those with a previous family history of dementia, the

emergence of the condition tended to be ascribed to bad luck or fate rather than genes, although concern was expressed about genetically transmitting the condition to children or grandchildren.

Temporality

All the accounts were, unsurprisingly, suffused with notions of temporality. A diagnosis of dementia brings people face to face with finitude, and is therefore likely to alter the ways in which they construct the past, present and future. People with young onset dementia face a shortened future than they might have anticipated, and difficulty accepting an altered future has been noted in other young onset dementia studies (Lockeridge & Simpson, 2012; Ducharme et al., 2013).

Temporal notions were evident in the ways people structured everyday time, and, similar to Locock et al.'s (2009) study of people with motor neurone disease, there was a general sense of making the most of the present. Derek, for instance, was engaging with more social activities, while Julia, Louise and Francine all reported becoming busier over the course of the fieldwork. Temporal rhythms seemed to become accelerated as holidays were taken more frequently and educational, campaigning and social activities were engaged in with greater regularity as increasing public interest in dementia created engagement opportunities. Activities were concentrated and, in contrast to participants in Årestedt et al.'s (2014) study, the tempo of lives (Adam, 2004) increased.

Members of third sector organisations encouraged the participants to plan for the future. Controlling aspects of the future such as creating a Power of Attorney seemed to liberate the present; once plans for the future had been put in place there was a sense that more enjoyment could be gained from day to day life. Louise, Josie and Francine expressed fear of the future, of not wanting to observe the final stages of dementia; for Louise, her previous experience as a nurse and as a family carer had brought her into contact with people who were in the later stages of the condition, and thus her past influenced how she constructed the present and the future. However, Louise demonstrated elements not just of the '*dreaded future*' (Charmaz, 1991) but also the '*everlasting future*', through

donating her brain to research, and the '*improved future*' as she sought to educate, campaign, and act as a dementia consultant. Julia (F2) originally seemed reluctant to consider her future, but as the fieldwork period progressed, and her condition deteriorated, she became more willing to consider her future needs.

All the participants with dementia in this generation experienced *fateful moments* (Giddens, 1991, p. 202) in the trajectory of their condition which created sudden, radical shifts in their sense of themselves as competent human beings, impacting variously on their previous identities, for example as an experienced and competent employee with a reputation of helping or training others, a well person, a multi-tasker, a mother with memories of her children's biographies, a person who knew his wife was dead or an independent person able to drive. Although others in the chronic illness field have highlighted turning points as a key aspect of chronic illness experience (Baumgartner, 2007; Jutterström, Isaksson, Sandström & Hörnsten, 2012), these events in the experience of dementia are, I contend, fundamentally destabilising as a person can become suddenly aware of not just something they are no longer able to do but of being affected by the loss of memory, a phenomenon which enables continuity between past and present (Post, 2006). Loss of memory, therefore, has the potential to radically affect the sense of the self in time, rupturing our ontological security (Giddens, 1991). Participants used their agency to attempt to counteract this loss of memory, for example, looking at images from the past in the form of photos to try to remember events and experiences. For Francine (F3), looking at photos of her family perhaps was an attempt to reassert or reconstitute her identity as a good mother which she seemed to perceive as fragmenting due to memory loss. By surrounding herself with family photographs her domestic space was filled with images of her children and grandchildren at different ages. This literal, temporal family display (Finch, 2007) was perhaps a constant reminder, conveying to herself her central and continuing role within her family.

As Morgan (2011) has noted, the dimensions of time and space are implicit within each other in family practices, and some participants in this generation used their agency to manage time and space in the context of young onset dementia. For Julia, for instance, a '*bad day*' required seclusion; a sequestering of her own time and space in the home that

other family members, with the exception of her dog, did not enter. Francine's preferred space and time seemed to be in her bedroom, rearranging her and Ron's clothes into colour order. This recreation of her working role in the home perhaps provided a means of reconstituting her ontological security.

Relationality

The three spousal relationships, between Louise and Jack, Julia and Peter and Francine and Ron seemed close and supportive. All three spouses were striving to find ways to adapt to enable their partners to live fulfilling lives, yet for Peter and Jack, it required no small degree of effort which could leave them feeling harried. As a result of their wives' dementia all three had taken on additional roles within the home, albeit to different extents. Peter took over virtually all the household duties, Jack, as the sole driver, became responsible for transporting their grandchildren and Ron also assisted more with care of the grandchildren, replacing Francine as the grandparent who could draw pictures. Initially Julia reflected on herself as being less of a person as Peter gradually took responsibility for the tasks she used to perform.

The men all became custodians in one way or another; Peter and Jack became responsible for scheduling time, while Ron was the person who had taken the most responsibility for seeking information and making decisions about what to share and what to withhold. All three, and Doreen (F5), were watchful and described the problems the person with dementia was experiencing, and how their shared lives were affected; the three husbands seemed to miss practices that they had previously shared together, such as watching and discussing television programmes (Jack and Ron) or attending the local social club (Peter).

Interactional disruption occurred in the spousal relationships. Difficulties finding words, misinterpreting the intentions of others, losing track of conversations and increased irritability could lead to frustrating communication, confirming findings from Oyebo et al.'s (2013) and Ducharme et al.'s (2013) studies. For Ron, Francine's difficulties distinguishing between his tones of voice disrupted communication, and Jack consciously

made efforts to '*stay on the same plane*' as Louise. For Ron, attempts at the start of the fieldwork period to normalise Francine's word confusion or memory loss transformed into a general minimisation of the importance of memory over time.

Pre-existing friendships seemed to play a substantial role for participants in this generation, particularly for providing respite. Julia and Peter's relationship with long-term friends Colin and Celeste seemed to strengthen over time, with Colin taking responsibility for arranging holidays and day trips. Louise's friend Josie kept her company every Saturday so that Jack could have respite, and Ron and Francine started to go on holiday with friends. However, not all the participants experienced strengthening relationships; Derek's pre-diagnosis friends became distant as he was no longer able to go drinking with them, and Jack reported that some of Louise's friends had stopped making contact. According to Cheryl (F5), Joan's retirement facilitated renewed intimacy with friends as she reconnected with her local community:

Cheryl: *She's also got... more involved in the village ... She joined the WI and she's been to quite a few of their meetings and enjoyed them. She enjoys the keep fit class they do on a Monday, because they are sort of all the old faces that we used to know when we were kids, who then, because of the job she had, became quite distant and now they've sort of come back together again*

Although little is known about friendships in the context of dementia (Harris, 2013) it appears from the evidence in this study that some friends respond to the condition by offering more help and taking more responsibility, even to the point where they are perhaps seen by some family members as overstepping relational boundaries, for example, by Violet (F2). Not all family members disapprove of the increased help of friends, however; Lauren's approval of Josie's support of Louise improved the relationship between them.

New friendships formed in support groups created the sense of a collective identity, of everyone being '*in the same boat*' (Jack, F1), corroborating findings from other studies (Telford, 2006; Tolhurst & Kingston, 2013). It is possible that the rarity of the condition, and the sense of breaching social norms by having dementia at a younger age, may have

created social spaces where bonds could quickly form. Apart from Francine's worry about making mistakes in social situations, the groups seemed to provide a non-judgemental, supportive environment.

Within this generation there appeared to be a lack of transition regarding relationships with siblings. For instance, Francine's diagnosis had not broken the communicative deadlock between her and her younger sister, and her relationship with her older sister also remained tense. Likewise, Julia's relationship with her brother, and their shared understanding of their mother's response, did not appear to have undergone major transition, although he was clearly distressed by her condition. Derek did not speak to most of his family, and although Louise's and Jack's siblings knew about her diagnosis, they were not mentioned in accounts of her dementia.

In general then, some people, whether friends or family, seemed more connected to the experience of dementia than others, and some relationships had undergone transitions as a result of the dementia while others had not. There seemed to be a sense of a selected set of relationships, characterised by '*strongly bounded*' (Morgan, 2011, p. 81) practices over shared time and space. Old friendships could be renewed and fortified, and new relationships seemed to be quickly formed in support groups. In contrast, apart from Lauren and Josie's relationship, there was no evidence that historically troubled relationships improved as a result of young onset dementia.

Individual and collective identities

All the longitudinal participants with dementia appeared to become more immersed in dementia-centric activities as time progressed, and the process of identifying more with the experience of dementia seemed to partially replace previous professional identities. Helping people was a core part of Louise's identity as a community nurse and she seemed to take pride in helping others with young onset dementia to join support groups.

Francine's identity as a mother and grandmother was also threatened by her dementia. Forgetting elements of her sons' childhood biographies and being unable to draw animals for her grandchildren caused sorrow; additionally she was clearly frustrated by her ability to remember aspects of her biography that she would rather forget, and to lose memories that she would prefer to retain. Charmaz (1995) described an identity hierarchy, in which ill people may have to sacrifice preferred identities for less favourable ones because of impairment. While this process implies some conscious decision-making, in the case of dementia there may be no choice. For Francine, her preferred identity as a mother is threatened by her loss of desired memories, and her less favoured identity as a step-mother remains intact because of memories she would prefer to forget. Additionally, her intact memory potentially reinforces a relational barrier between Ron and his son.

New identities started to be forged over the period of the fieldwork. In some cases, these were positive experiences, such as Louise's activism and Julia's educational activities, but Francine saw herself as an increasingly nervous person, struggling to make decisions and losing confidence at familiar events.

The adult children generation

Eight people within this generation gave accounts: Eliza (F2), Laurence, David, William and Marie (F3), Annie (F4) and Cheryl and Craig (F5). Other significant people to be mentioned were Louise and Jack's daughter Jessica (F1), Naomi, the younger sister in F2, and Cheryl's brother George.

Making sense of dementia

Several people in this generation constructed meanings of dementia in the context of their previous experience of the condition or of other serious illness. Annie (F4), for example, worked with people largely in the later stages of dementia, and expressed relief that her father's diagnosis was Korsakoff's syndrome rather than, as initially thought, Lewy body dementia, which she perceived that people *'end up like a vegetable, there's*

nothing there at all'. For Cheryl (F5), her brain injury had caused her to have severe memory loss, and her experience of Joan's dementia caused her to reflect on how her family must have been affected by her injury. The emotional impact of dementia, and the upset when her mother forgot something, or regressed back to an earlier stage in her life, was distressing; she contextualised dementia by comparing it to cancer, expressing almost an envy of a cancer diagnosis because *'it's a nightmare, but your brain still works. You're still that same person'*.

Eliza's husband (F2) had been diagnosed a few years previously with a form of leukaemia, and she made sense of her mother's dementia in light of her response to her husband's illness. Furthermore, members of F3 expressed the view that Francine's development of dementia was unfair, given all the other illnesses she had experienced. Rolland (1984) has suggested that practitioners need to develop awareness of a family's previous experiences when supporting them to deal with illness, and this study confirms that meaning-making processes are embedded in and shaped by health problems encountered in the past.

Annie and Cheryl felt that the experience of dementia was worse for family members who could do little but watch as someone started to decline. Eliza too expressed a sense of powerlessness. Annie, and reportedly Cheryl's brother George, both expressed the opinion that they would prefer to be euthanised or to commit suicide if they developed dementia rather than have their family witness their decline.

While people in the older generation above did not appear to consider the age of onset as particularly pertinent, it was highlighted by some participants in this generational stratum (Eliza, F2; Annie, F4; Cheryl, F5), perhaps suggesting Bury and Holme's (1991) *'social clock'* had more significance for these participants.

None of the participants in this generation attended the support groups, even though some had been invited. Similarly, none were in regular contact with the dementia charity, although they were aware that they could contact them if need be. The need for age-

sensitive services, an issue frequently raised in the young onset dementia literature (e.g. Beattie et al., 2004; Chaston, 2011), was emphasised by some (Annie, F4; Cheryl, F5).

Participants were aware of the diverse experiences of dementia, and argued that everyone experiences dementia differently (F2 & F3). In some cases this seemed to be a way of reassuring their relative with dementia that their future experience may be very different to the deterioration they had witnessed in others at support groups.

Temporality

For several of the participants, there was an emphasis on focussing on the present and on the remaining abilities of the person with dementia rather than the future (Eliza, F2; Laurence, David & Marie, F3; Annie F4). There was a sense expressed that occupying time productively day to day was important and the stability of a routine helped the person living with dementia to be motivated and stimulated (Annie, F4; Craig, F5).

The day-to-day uncertainty of the person with dementia's state of mind was seen as potentially problematic, and the lack of predictability of good days and bad days meant that, for some, taking life day by day, and relinquishing notions of an extended future, was an important coping mechanism (Eliza, F2; Annie, F4; Cheryl, F5), supporting Allen et al.'s (2009) findings.

In common with participants in other studies (Forrest Keenan et al., 2007; Svanberg et al., 2010), maintaining a positive attitude and normalising memory loss and accidents was seen as particularly important by Laurence, David, William & Marie (F3) to try and counteract Francine's anxiety and lack of confidence. They portrayed home and family as non-judgemental havens where the effects of dementia would not have an impact on her sense of self.

Relationality

Proximity was a concept that seemed relevant to some of the participants in this generation. For Craig (F5), living in the same locality as his mother-in-law Joan was crucial; he noted that his brother-in-law George was less connected to the family-experiencing-dementia partly through his geographical distance but also his apparent reluctance to accept the condition. Laurence, the eldest son in F3, noted that his mother's dementia had made him less selfish and more inclined to share space and time with her. Being available to the person with dementia seemed to be a key experience for all of the participants in this generation.

Some of the adult children in the sample expressed the view that they wished their relative to remain independent for as long as possible (Laurence, David & William, F3; Annie, F4) and were actively trying to support them to do so, discouraging the adoption of services, like the dementia charity's one-to-one service, before they were required.

Members of F3 continually questioned the boundaries between what is normal behaviour and what can be ascribed to dementia in an attempt to alleviate Francine's anxiety. However, their efforts did not seem to be effective as Francine continued to worry, and may even have felt that her expressed concerns were not fully validated by her children.

Supporting Flynn & Mulcahy's (2013) findings, balancing competing needs also seemed difficult; Eliza (F2) stated that being available to her parents had to be balanced with leading her own life. Craig and Cheryl (F5), also had competing concerns about caring for their autistic son and Cheryl's own health.

With two of the families, F2 and F5, there was a sense that some family members were not responding to the increasing need of the person with dementia. George (F5), for instance, was perceived to be leaving difficult decisions to sister Cheryl, and Naomi (F2), in contrast to Eliza, was not actively offering help. Thus through relational practices there was a sense of some participants distancing themselves from the family-experiencing-

dementia, corroborating the findings of Svanberg et al. (2010) and Hutchinson et al. (2014).

The youngest generation: grandchildren of people with young onset dementia

There were grandchildren in all five families in the study, but permission was only given for one young person, Lauren (F1), to be interviewed, whose account is reported in depth in Chapter Six. Attempts to interview children in families where one person had young onset dementia were also met with resistance by Roach et al. (2013), who could not recruit any young people to the study.

Although this was disappointing, it must be realised that participants wish to protect their children from the effects of illness (Emiliani et al., 2011; Roach et al., 2013), and hence may not feel that it is appropriate to engage them in research. In the near absence of first-hand accounts I made efforts to ask about the perceived effects on or knowledge of the grandchildren in all the families, and there are therefore in this section reference to : Leo (11 years old) and Lucy (7, F1); Joshua (12) and Shannon (9, F2); Jamie (10), Eva (7), Natasha (12) Molly (10) and Cameron (8, F3); Max (8, F4); and Scott (17) and Ethan (15, F5).

All the grandchildren in this generational stratum had been informed of their grandparents' diagnoses, however, there was a sense expressed that no further discussion had taken place, apart from with Lauren. A similar finding was noted by Johannessen and Möller (2011), who found that young onset dementia, while not being concealed, was rarely discussed within families. In general, people constructed their views of how much grandchildren knew about the condition by their age and perceived maturity; for example, Julia (F2) perceived that it '*went over*' Shannon's head, Laurence expressed the view that all the children in F3 were too young to notice, and Cheryl (F5) commented that her two teenaged sons were now '*old enough*' to be aware of the condition. Similarly William (F3) reported that his eldest child knew a '*little bit*', because

she was old enough to be in secondary school, but that his middle daughter would only have a limited understanding.

However, on close examination of the dataset, there are clear hints that the grandchildren were, in fact, observant of changes within the family. Naomi (F2), for instance, was prompted to tell Joshua about the diagnosis at age 10 because he had been aware of her and her husband '*whispering*' about grandmother Julia. Max (F4) became upset when his granddad Derek forgot to read him a story, and David (F3) reported that his daughter Eva had told him that their grandmother Francine was unable to recognise an animal on the television, and that she had had to tell her what the animal was. Shannon (F2) was at the least aware of her grandmother's visual difficulties, as reportedly she would help her avoid stumbling on tree roots while out walking the dog. Cheryl (F5) reported that her sons had asked her why they were no longer staying with their grandmother at weekends, and going out on day trips with her.

Therefore, in all the families, there were instances where grandchildren had become aware of their grandparent's difficulties, even from seven or eight years old. Although these are small fragments of data, showing that the children and young people observed disturbances in sedimented family practices, it is possible that, like Lauren, the grandchildren were reluctant to verbalise observations to their parents or grandparents for fear of upsetting them, therefore probably, again like Lauren, leaving them no opportunity to talk about any concerns they might have.

There was also evidence that some of the grandchildren acted in ways to assist their grandparents. Shannon, in particular, liked to help her grandmother Julia, and Leo (F1), who was reportedly uninterested in Louise's dementia, started to become more helpful by the end of the data collection process. Millenaar et al. (2013) found that children of people with young onset dementia mature more rapidly to enable them to take care of parent, and a similar process may be occurring in some of the grandchildren in this study. Lucy (F1) often helped with household tasks, although it is difficult to know whether her actions were based on awareness of her grandmother's condition. Joshua (F2) was perceived by Julia to be acting against the norms both of his gender and developmental

stage by offering her smiles and embraces. There is an absence of evidence on the experience of grandchildren in the context of young onset dementia and this evidence can therefore not be contextualised within the knowledge base on this subject.

The contribution of symbolic interactionism, belonging, family practices, the sociology of personal life and QL research to the understanding of illness experience

Throughout this thesis I have suggested that existing knowledge of illness in general, and young onset dementia in particular, while offering important insights into insider perspectives, is limited by an emphasis on individual experiences and biographies. I contend here that using a QL approach and a theoretical lens of belonging, family practices and the sociology of personal life to studying intergenerational relationships has offered a different insight into illness experiences; by drawing attention to historical and generational, as well as entwined biographical time, we can elicit richly textured insights into the complexities and challenges of living with a progressive condition such as young onset dementia.

The notion of identity transitions has been a dominant influence on the sociological knowledge base and has generated important understandings of illness experience. However, May's (2013) argument that the concept belonging offers a more relational view than identity is important here; for instance, while we know from research that ill people can become immersed in their illness experience (Charmaz, 1991; Baumgartner, 2007), and the ill identity can dominate their conceptions of self, less attention is drawn to relationality, and the processes by which meanings of illness are socially negotiated over time. Returning to Harris and Keady's (2009) quote, that '*dementia touches all members of the family*' (p. 442), I argue that the evidence from this study demonstrates that members of a family, and of a friendship network, are indeed affected by dementia, and that some 'belong' to the experience, and that this belonging is mediated and reconstituted through strongly-bounded relational practices over time.

There is a multiplicity of intersecting ways in which people connected to the experience of young onset dementia 'belong': to historical time, to a generation travelling through that time, to their personal family and friend relationships, to support groups, to the research process, to work, to place and to their past, present and future. Although other young onset dementia studies have found that young people and adult children choose to distance themselves from the person with dementia (Svanberg et al., 2010; Hutchinson et al., 2014), what this study illuminates is the more complex processes by which people belong or do not belong to the experience of young onset dementia, with historical family relationships emerging as a key indicator; where there was existing conflict, dementia emerged as another conduit through which tensions were played out within family practices, rather than as a reason to resolve troubled relationships. In contrast, where families viewed themselves as close and supportive, the presence of dementia seemed to renew the importance of shared family time. Thus young onset dementia, from the evidence of this study, augmented or reinforced rather than revolutionised relational practices.

Friendships, often assumed to diminish in dementia (Harris, 2013), were an important and ongoing part of the lives of the participants in this study, and it was possible to observe some elements of the '*friendship career*' (Spencer & Pahl, 2006) as Colin and Celeste (F2) became increasingly involved with assisting Julia and Peter over the twelve-month data collection period. Colin, in particular, seemed to enable Peter to reflect on his sense of self as a person needing support; there was gratitude rather than any sign of resentment regarding the increased commitment. The characteristic of the friendship could be seen as '*suffusion*', a blurring of the non-kin/kin boundaries, which reportedly caused jealousy and resentment from Violet, which, perhaps ironically, reduced her belonging to the experience while increasing theirs.

Louise's long-standing friend Josie (F1) seemed to view herself as facilitating a connection between the present and Louise's professional past. According to Josie, reliving their shared past helped Louise to retain confidence in the reliability of her own memory, and, as Giddens' (1991) might argue, bolster Louise's ability to be self-reflexive through stabilising her autobiography. Indeed, Josie's belonging to the illness experience seemed

bound up with Louise's memory; her expressed fears of Louise forgetting her in the late stages of dementia seemed to signal the point at which, through distress, her involvement would cease: *'I don't want to see her like that, like she is at the end'*.

The importance of friendships in the context of the participants' lives raises questions about whether the sociology of personal life (Smart, 2007) is a more appropriate theoretical lens than family practices (Morgan, 2011) to understand relationality in the context of young onset dementia. I concur with May (2012) who suggests that *'it is very probable that we need both a family sociology and a sociology of personal life to capture the nuances of human life'* (p. 420). In this study, family was certainly the starting point of the inquiry - participants were selected on the basis of family - but the significance of non-kin relationships with existing friends and support group members soon became apparent. A broader understanding was, therefore, necessary; a purely 'family' focus would have overlooked the significance of Celeste, Colin (F2) and Josie (F1), and the influences of Lauren's (F1) peer group. Nevertheless, certain elements of the data bore the hallmark of family. For instance, Francine's anxiety about her sons' inheritance of their grandmother's money should she predecease her is immediately striking as a kin issue, concerned as it is with the institution of family transferring resources down generations. Similarly, Lauren's (F1) experience of her grandmother forgetting when her mother's ashes were scattered poignantly portrays how dementia can impact not only on our relationships with the living but also with the dead, and on constructions of the significance of ancestry to personal lives. I argue that, however problematic the concept of family may be, suffused as it is with unwelcome heteronormative baggage, its time in the sociological lexicon is not over yet.

There was a generational dimension of belonging; with the exception of Lauren, members of the oldest and youngest generations were not, either through perceived lack of acceptance or lack of knowledge and maturity, viewed by members of the other two generations as being part of the experience of young onset dementia. Thus two boundaries seemed to be drawn around the family-experiencing-dementia, a moral boundary which excluded parents and siblings who had developed poor reputations (Finch & Mason, 1993), and a perceived awareness boundary which excluded all but one

of the grandchildren. This raises the question of what is different about Lauren and the relational context in which she lives. It is a difficult question to answer, but I would suggest that her sense of agency, her eagerness to know more about the condition, and her desire to help her grandparents, who, in the context of her father's untimely death, have been central figures in her life, has given her a greater connection to the illness experience.

While focussing primarily on family, yet also drawing attention to relationships that are neither genetic nor affinal, this study also demonstrates some of the complexities of kin/non-kin relational boundaries in the context of young onset dementia; for example, Violet (F2) is perceived to be jealous of Colin and Celeste and resentful of their involvement with Julia's experience of PCA, and Josie (F1) expresses concerns about the effect of Louise's increasingly active life on Jack's well-being. Therefore, although intergenerational families are the starting point in this study, and family practices provides a useful way of understanding processes within families, the sociology of personal life broadens empirical attention to significant relationships with others.

One of the notable distinctions between the young onset dementia literature and the sociology of chronic illness literature is the use of theoretical frameworks. I have observed that the subjective experience of young onset dementia knowledge base is largely atheoretical. In contrast, the sociology of chronic illness predominantly uses Bury's (1982) biographical disruption and Charmaz's (1991) work on self and identity transitions to understand the processes experienced by ill people. I suggest that these frameworks have utility in the analysis of young onset dementia experiences, despite the fact that they are individualistic in orientation and pay little explicit attention to the context of enmeshed relationships. Returning to the tension in the sociology of chronic illness field identified in Chapter One, regarding the utility of theoretical constructs within the particularistic contexts of the lived experience of illness, I argue that constructs such as biographical disruption can be meaningful; within this study, for example, the challenges to professional and maternal identities and the need to reframe a sense of self have been observed. However, it is necessary to establish the limitations of concepts through interrogating contextual particularities, and I suggest that the biographical disruption is

more profound in the context of young onset dementia, when the discontinuity between past and present is compounded by memory loss, posing a more potent threat to ontological security.

Consistent with a qualitative longitudinal methodology, temporality is an explicit element of this work and this distinguishes it from the existing young onset knowledge base, which makes reference to the loss of futures (e.g. Oyeboode et al., 2013) and to coping strategies to assist with the present (Lockeridge & Simpson, 2012) but does not explore temporal rhythms, or generate concepts such as accelerated intimacy or the liberation of the present through the controllable future. Temporal themes form a more visible strand in the sociology of chronic illness literature, with several authors discussing the reconstruction of the past, present and future in the context of illness (e.g. Carricaburu & Pierret, 1995; Lawton, 2003; Jowsey et al., 2013). However, caution is needed. For instance, Charmaz's (1991) typology, (the dreaded future, the improved future, the taken-for-granted future and the everlasting future) offers insights into how ill individuals conceptualise their futures but may potentially lead the reader to assume that a person's outlook falls neatly into one category. In Louise's (F1) case, however, it was possible to discern how her vision of the future encompassed three of the four almost simultaneously.

Historical time and the prevailing socio-political context at the time research is conducted is rarely referred to either in the sociology of chronic illness or the young onset dementia bodies of literature, and it can be argued that this is a weakness, perhaps particularly so when an illness is in the public spotlight, as dementia has been in recent years (Alzheimer's Society, 2015). Presenting data in an ahistorical way devalues the importance of context, neglecting the intertwining of history, generation and biography, and as sociologists we must continue with our longstanding efforts to understand the interplay between individual lives and social change (Mills, 1959). This study illuminated participants' awareness that dementia was receiving more attention at governmental level, that services and research were attracting more public funding, and that dementia was becoming more visible in popular culture. As has been observed in this thesis, some participants (in particular Louise, F1 and to a lesser extent Julia, F2) have engaged with

the social movement of dementia, developing new identities as campaigners and educators.

Using the perspectives of family practices (Morgan, 2011) and family displays (Finch, 2007) rather than a static, unified view of 'the family' has drawn attention to the fluidity of relationships, and elucidated belonging and not belonging to the experience of dementia over time. The processes by which information about dementia flows within families, the ways in which people seek to protect others, and the ways in which people gain roles or reputations in relation to the condition are shaped by the long-standing relationships between them. There are some links between this work and that of Roach et al. (2013), who identified five family storylines: agreeing, colluding, conflicting, fabricating and protecting. These different relational patterns offer a useful way of conceptualising family relationships in the context of young onset dementia and each of them could be applied to my dataset. In F2 alone, for instance, there could be a combination of 'agreeing' between Julia, Peter and Eliza, 'colluding', as the three participants tried to increase Naomi's level of commitment, 'conflicting', in the relationship with her parents, 'fabricating', when they initially lied to friends about Julia's condition, and 'protecting', as, apart from the disclosure, Julia's dementia was not discussed with the grandchildren. However, trying to fit the data into these categories runs the risk of obscuring the multifaceted nature of the experience, and does not draw sufficient attention to the meaning-making processes shaped by the historical context of relationships, to temporality, intergenerationality, friendships, the role of support groups or the socio-political climate in which young onset dementia is experienced.

A greater focus on meaning-making processes, through the overarching perspective of symbolic interactionism, has explored how meaning arises intersubjectively, actions that are taken on the basis of meaning and how meanings are modified over time (Handberg, Thorne, Midtgaard, Vinther Nielsen, & Lomborg 2015). For participants in this study, a core feature of this process was constructions of normality and difference. For Ron (F3), for instance, a key transition in meaning was moving away from a position of normalising Francine's memory loss, to minimising the significance of memory in general. In F2, Julia perceived herself to be positioned somewhere between normal and 'mad' through

comparison with others and in F1, Louise's meaning-making processes forged a new identity as an active purposeful citizen.

The contribution of an intergenerational qualitative longitudinal approach to dementia research

I have aimed to demonstrate through this thesis that adopting a qualitative longitudinal methodology provides holistic temporal and relational insights into the intergenerational experience of young onset dementia; insights, I argue, that dementia research conducted within more traditional paradigms would not produce. For instance, knowing that Jack sometimes experiences stress in his role as Louise's husband is an interesting finding in itself, and, using a positivistic research design, his stress could have been quantitatively tracked over time using a burden scale. Perhaps it might have shown us that his stress score had increased over the year, again an interesting finding. But this information would not be able to tell us that a major cause of that stress is feeling harried due to an increased tempo in their lives, and that the reason for the increase in tempo is that the social movement of dementia is creating opportunities for Louise to engage more intensively in research, activism and education. Furthermore, it would not tell us that his commitment to Louise and his desire to support her sense of self-worth leads him to make tiring efforts to help her to fulfil her ambitions to be a dementia activist. Nor would it describe his evident joy and pride when she changes the entrenched attitudes of a nursing sister, thereby potentially improving care for many other people living locally with dementia. Furthermore, we would remain unaware that his grandchildren Lauren and Leo know of his struggles and are actively managing space and time in the home to try and alleviate his stress.

Taking a biomedical perspective to generate an understanding of Julia's condition would entail regular tests of her cognitive competencies and visual acuity and would provide scientific evidence of her functional decline over a twelve-month period. Yet that would give no information about the complexity of Julia's enmeshed relationships and the ways in which she faces the challenges wrought by PCA. It would say nothing of the

indomitability of her spirit, the delight taken in her triumph over diabetes, her determination to enjoy holidays, her troubled relationship with her parents or her embodied connectedness with her grandson, brother and dog. Nor would we learn about the ways in which her participation in support groups has enabled her to make valued, meaningful connections with others, or about how she has come to feel at peace about her future care and her death.

Thus, a QL approach, by drawing attention to the intersection of biographical, generational and historical time, enables a fascinating, multi-layered insight into meaning-making processes that can occur within families when one person develops young onset dementia. I contend that the theorising stances of belonging, family practices and the sociology of personal life can be fruitfully used by other health and illness researchers who have an interest in exploring the effects of illness beyond the ill individual or the carer/cared-for dyad.

Original knowledge

Naturally, I make no claim to generalise in a probabilistic sense to state that all families living with young onset dementia have similar experiences to my participants. However, I contend that concepts and findings have emerged from this study that have the potential to elucidate the experiences of others. Returning to Bertaux and Delacroix's statement, that even one family may enclose a '*sociological pearl... whose awareness might illuminate thousands of other cases*' (2000, p.83), I suggest that my work with a small number of families has generated concepts that have contributed unique knowledge to the field in the following ways:

- Transgenerationality: the notion that a grandparent with dementia may be perceived not to be relocating themselves in their own childhood, a known phenomenon in dementia, but to reposition themselves in their grandchild's generation, becoming more of a peer/ friend to their grandchild than a grandparent through engaging in actions associated with that generation

- Some family members and friends belong to the experience of dementia, and others do not, and the processes by which this occurs are through ongoing relational practices
- Parents of people with young onset dementia may find it difficult to accept their child's condition, may have unrealistic expectations of their capabilities and may have concerns about the availability of family resources for their own future care
- Grandchildren of people with young onset dementia are often presumed to be unaware of their grandparent's dementia, and that, after the initial disclosure, it is not referred to again, unless the grandchild demonstrates an obvious interest. However, the evidence from this study suggests that grandchildren can be acutely aware of their grandparent's difficulties but may lack space to discuss it with family members
- The presence of young onset dementia is perceived to strengthen the bonds between family members where people already see the family as close and supportive, but does not provide a reason to resolve troubled relationships
- Accelerated intimacy can occur within support groups as meaningful friendships form quickly in non-judgemental spaces, mitigating against the feeling of being alone with young onset dementia. However, support groups can be initially daunting, as witnessing others at a more advanced stage of the condition can be perceived as foreshadowing their own future
- The increasing public profile of dementia has enabled some participants to refashion their identities, creating opportunities for them to become involved in activism, education and consultation

Limitations

This study has provided unique, nuanced pictures of intergenerational experiences of young onset dementia. However, there are several limitations of the study which should be brought to light.

Firstly, and in common with other QL studies (Saldaña, 2003; Farrall et al., 2016) there was sample attrition as two families withdrew from the study after the first wave of data collection. Therefore their experiences could only be viewed from a synchronic rather than a diachronic perspective.

Secondly, not all family members participated in interviews. As has been argued, involvement in this research study was likely to be connected to the complex processes of belonging or not belonging to the experience of dementia. Therefore, there is only proxy data about those who were not invited by family members to participate, i.e. all but one of the grandchildren, and those who were invited but opted not to, for example, the parents. Gabb (2008) exhorts us to remember that researching private family life is, in itself, '*sensitive topic*' research (p.21). In this study the sensitivity is compounded by the nature of the research subject area, i.e. progressive illness, and further compounded by the fact that the condition can affect decision-making capabilities and may possibly be transmissible genetically. In my view it is unethical to be overly persistent in attempting to recruit family members to a study such as this, and, moreover, a dogged approach, I would argue, is likely to result in more attrition than I experienced. To expect to interview all family members is ingenuous, as both I and Roach et al. (2013) discovered; future researchers in this field would be advised to work closely with facilitating organisations to try and identify individuals or couples who would be willing to commit to the term of the research and who are likely to facilitate access to a number of family members and friends.

Another limitation is the length of the data collection period. Following families for several years would undoubtedly create a more sophisticated account of the experiences of young onset dementia, and may capture key transitions such as admission to a nursing

home. However, within the time constraints of a full-time PhD, I argue that year-long data collection is the maximum feasible fieldwork period, especially when there may be short intervals between the commencement for each family. Data collection periods for several of the QL studies in the Timescapes initiative were only slightly longer, at around 18 months (for example Bornat & Bytheway, 2014; Neale & Lau Clayton, 2014) and I argue that while a year is a relatively short period of time, fascinating continuities and transitions can be captured and represented.

A key limitation of the study is that all the sample were in receipt of support services. This study has revealed the importance of support group membership in the lives of the people with young onset dementia, thus those living without contact with others living in similar circumstances are likely to have a very different experience. Future studies should make attempts to contact those who may not be in receipt of services.

In terms of social stratification there are limitations in the sample. There was little ethnic diversity: all participants were either white Irish or white British. The range of occupations represented ranged from unemployed through to semi-skilled manual, skilled manual and lower managerial. There was no representation from the upper/capitalist classes. In addition, all of the participants appeared to be in heterosexual relationships; hence there was no known representation from LGBT+ communities. Finally, all the longitudinal participants with a diagnosis of young onset dementia were women, hence there is no diachronic data on men's experiences. Although attaining a diverse sample is complex due to the rarity of the condition and the willingness of people to commit to longitudinal studies, future researchers could attempt to recruit more heterogeneous samples.

A reflexive note

It has been my aim throughout this research to approach the field with as few preconceptions as possible; respecting and attempting to illuminate the everyday and making the taken-for-granted more visible. I cannot abstract myself from my own lifecourse and historical time, and therefore the ways I have approached the research are

shaded by my own interests, assumptions, motivations, emotions and moral stance regarding family relationships; mediated, but not determined, by the social structures shaping my own biography. A major assumption that underpins my approach is that lives are constantly in a state of flux; even seemingly static experiences, are, I contend, continually reproduced through social action rather than steadfastly enduring.

Ethically, I struggled with competing desires: to know more by asking difficult questions and to protect my participants from being pressed to consider difficult and distressing future scenarios. As Swain, Heyman and Gillman (1998) have suggested, research which aims to give voice to vulnerable groups can itself be exploitative, and, at times, there was internal dissonance between the motivations of a scientist wishing to generate knowledge, a researcher wishing to act as a conduit for the experiences of a marginalised group, an academic seeking a qualification to further her career and a compassionate human being wishing to protect people from distress.

Ethical issues are heightened when the research design is longitudinal. It is important to recognise that implicit in Neale's (2012) assertion that QL researchers walk '*alongside*' participants is that they walk *with* them. The ways in which the knowledge generated by the study has been shaped by the evolving relationships between myself and my participants are difficult to articulate in a comprehensive way, since it is likely that I am not entirely conscious of them (Mauthner & Doucet, 2003). However it seemed to me that participants became more trusting as rapport developed over time, and interactions that had more of a professional, formal character in wave one became more reciprocal and conversational in later waves as participants would remember and refer back to things I had told them about myself and my own family. I contend that research of this nature blurs the boundaries between professional and informal relationships, and qualitative research and therapy. I have no pretensions to possess therapeutic skills, but the mere creation of a space where family members can talk together, often for the first time, about deeply concerning sensitive issues undoubtedly creates opportunities to share information, to reassure each other and to develop co-constructed meanings. Relationship research, as Bancroft (2011) has noted, is especially complex as '*the researcher has a relationship not just with the participant, but also in a sense with their*

relationships' (p. 71), and being permitted access to these relationships is a privilege accompanied by complex responsibilities.

As recommended by Jamieson (2011), I have tried to stay conscious of the ways in which my emotions have affected my portrayals of the participants. While good relationships developed with all the participants, I preferred the company of some to others and this may have affected the way I presented their stories. I acknowledge that I was particularly impressed by Julia's indomitable spirit, perhaps best exemplified in her statement: *'I don't know what having the sight is all about, 'cause you can always work around it, I think'* (Wave Three) and by her plan to fundraise for the charity by doing a Wing Walk. I very much doubt I would face her circumstances with the same courage and grace. I was similarly impressed by Lauren; her moral commitment to her grandparents, the ways in which she diligently sought and interpreted information about dementia, her acknowledgement that she could never fully understand her grandparents' experiences, and her disdain of what she considered to be the trivial diversions common to her peer group.

I propose that the feeling of debt researchers often have to their participants is amplified during longitudinal research, and I remain very grateful to them for their involvement in the study. Nevertheless, and bearing in mind Gabb's (2010) caution that researchers can feel that they are betraying families who have generously given so much of their time, I have attempted to capture and represent their accounts as authentically as possible including the conflicts and the disagreements as well as the love, care and commitment demonstrated by the participants to each other.

For my part, I endeavoured to treat my participants with respect, and, while not personally offering help or answering anything other than the most straightforward questions about dementia, have signposted them on occasion towards the relevant charity if they raised an issue of unmet need. I asked participants to reflect on the research process, and they all stated that they had enjoyed having the chance to talk, but, more importantly, that they felt that they could be helping others through the research project. For example, Julia and Peter stated:

Julia: I'd rather be talking about stuff than [Peter: Definitely, yeah] not, because then, you know, you do things like that then at least you..

Peter: You feel good about yourself that it might help other people out
(Wave Three)

Therefore, it is incumbent on me to disseminate this work to best effect, in the hope that, however small this study may be, there may be some impact on practice, policy or future research.

I have been very deeply affected by working with these participants, not just over the 12-month data collection period, but every time I re-read interview transcripts. As I read their words, I hear their voices, and the black and white of ink on paper is transformed into a richly-textured, multi-sensory memory. Knowing that some of them have a progressive condition, and that it is likely that their dementia has advanced since I last saw them, is difficult to accustom myself to. I developed a fondness for all the participants, particularly those who stayed in the study, and my most enjoyable times with them were not when we were talking about dementia, but when they were telling a funny story about something that had happened in the past. Watching them all chip in parts of an anecdote, talking over each other, often helpless with laughter, made me very conscious that while young onset dementia was a reality in their lives, it was far from being the defining characteristic.

Concluding comments

In summary I contend that the use of a QL approach with a sociological focus on relationality has created new insights into the intergenerational experience of young onset dementia over time. While identity transitions have long been a focus of sociological investigations into illness, I contend that the use of belonging offers a broader focus, exploring how illness impacts on enmeshed intergenerational relationships, and that this orientation, therefore, offers a more holistic view of the experience of young onset dementia.

The final chapter of the thesis uses the key findings of the study to offer recommendations for policy, practice and future research.

Chapter Eleven: Conclusions And Recommendations

Introduction

This exploratory study has provided important insights into intergenerational experiences of young onset dementia that can contribute to debates on health and social care policy and service provision. This final chapter will complete the thesis by drawing together key findings to discuss recommendations that can be made to support people and their families and friends to live well with young onset dementia. Additionally, there is a consideration of the contribution sociology can make to generate understandings of the experience of dementia. The chapter concludes with a brief personal reflection.

Recommendations for policy

Kitwood's (1997) work on personhood and dementia undoubtedly caused a seismic shift in the paradigm of dementia care. By drawing attention to the ways in which people with dementia were undermined through a range of detrimental relational practices termed '*malignant social psychology*' (p. 46), Kitwood provided an alternative means of conceptualising the experience of dementia which gave primacy to the personhood of each individual. The foundations Kitwood laid form the cornerstone of the dominant model of person-centred care which acclaims the uniqueness of each individual living with dementia and calls for care tailored to their particular circumstances.

There is a general consensus that Kitwood's work and the principles of person-centred care should be enshrined in dementia care and his recommendations have endured largely without critique. However, taking a sociological perspective, both Davis (2004) and Jenkins et al. (2016) suggest there are limitations to Kitwood's position, with the former suggesting that carers can feel alienated if they perceive their attempts to maintain the personhood of the person with dementia fail as the condition progresses, and the latter arguing that person-centred care is overly individualistic in orientation and reinforces polarisation implicit within the carer-cared for dyad.

More recently, there has been a shift towards relationship-centred care, which focuses on how significant others can be supported to enhance their relationships with the person with dementia and how carers can become partners in the care process (NICE & SCIE, 2006, updated 2016). However, although guidelines make reference to family and friends, 'carer' is the predominant concept, and one which has been previously challenged for drawing attention to a single person in the web of relationships, constructing asymmetry, neglecting the effects of illness on others and creating narrow role definitions of people as either receivers or givers of care (Molyneaux et al., 2011; Jenkins, 2014; La Fontaine & Oyebode, 2014).

I argue here that there needs to be a broader vision for policy which enables the construction of channels through which voices of all generations, both family members and friends, can be heard. As this research has shown, members of different generations are affected by dementia in a multitude of ways, and a narrow focus on the carer-cared for dyad does a disservice to people, especially, perhaps, young people like Lauren, who would not be considered 'carers' but who may have no arena in which to discuss concerns and challenges, and who may try to manage anxiety and distress in silence. Similarly, the voices of parents of young people with dementia are absent in policy and research arenas, and they deserve to be supported as they seek to understand the effects of the condition on their child.

Recommendations for practice

I have grouped the findings and recommendations for practice into four key areas: intergenerational families and friends, day-to-day life, information and support services.

1. Intergenerational Families and Friends

A key finding from this study is that different generations within a family are affected by dementia, and that an intergenerational care model would be appropriate to provide support for people living with young onset dementia. The following suggestions offer ideas for consideration for practitioners:

Suggestions for practice

- Broaden the vision from the person with dementia and/or the primary carer to encompass other significant relationships, offering age-appropriate information and support
- Develop a sensitivity to the unique circumstances of the family and friends to understand how people make sense of dementia and how it affects relationships
- Encourage family members to consider counselling or mediation services where relationships are difficult
- Encourage the maintenance of existing friendships

2. Day to Day life

Ways in which the day-to-day lives of people living with young onset dementia could be improved are by:

Suggestions for practice

- Providing training in communication skills to reduce interactional disruption
- Working with employers to enable people with dementia to stay in work for as long as they wish to, or explore the possibilities of voluntary work for people who are struggling to adapt to early retirement
- Providing opportunities for people with dementia to become educators, activists or fundraisers
- Helping people to develop routines and strategies to make the most of the

present

- Provide counselling services for people with dementia to enable them to make sense of dementia
- Offer a badge or card to people with dementia that can be used in public areas to explain difficulties or ask for help
- Raise awareness of young onset dementia among the general public, businesses and shops

3. Information

This study has identified a range of information needs, and services could aim to:

Suggestions for practice

- Provide credible sources of information for families and an opportunity to discuss any worries about genetic transmission and memory loss
- Educate health professionals about rarer forms of dementia
- Provide an arena for people to discuss difficult decisions they might have to make about their relative's future
- Work with schools to educate children and young people about dementia

4. Support groups, day care and one-to-one services

Evidence from this study has highlighted the significant role that support groups play in people's lives. However, a few issues were noted with these and other forms of support which could be addressed:

Suggestions for practice

- Support people to continue attendance at support groups even though initial visits may be disconcerting
- Explore options to provide day care for younger people with dementia
- Explore ways to make support groups diverse and inclusive
- Work with families to ensure timely provision of services

Towards a sociology of (young onset) dementia

As Tolhurst and Kingston (2013) noted, a sociology of dementia is in its infancy and there is much work to be done to develop sociological understandings of a condition which is the global health challenge of our generation. Nonetheless there have been several interesting excursions into sociological and philosophical territory; for example Tolhurst and Kingston's (2013) use of Glaser and Strauss' model of status passage, Kontos' (2004) integration of Merleau-Ponty's and Bourdieu's theoretical frameworks and Davis' (2004) consideration of Foucault's, Merleau-Ponty's and Heidegger's perspectives in relation to dementia. More recently Jenkins (2014, Jenkins et al., 2016) have taken an interactionist perspective to argue that rather than attempting to reconnect people with dementia to a pre-morbid discrete self, we should aim to facilitate the emergence of a '*montage of selves*' (2014, p.125) through respecting the transactive nature of people, and the continually emerging rather than unified coherent self.

Here I offer a slightly different conceptualisation of dementia, which respects Jenkins' (2014) interactionist focus on the emergent self but broadens the vision to consider the ways in which people may 'belong' to the experience of dementia. From this perspective, as I have demonstrated, we can explore the dynamics of intra- and intergenerational relationships, gaining important insights into relational practices in family and friendship networks. However, since we now have a '*call to the whole of society*' to improve care for people with dementia (Department of Health, 2013, p. 4), the concept of belonging may also be a useful conceptual tool to understand processes within the creation and maintenance of dementia-friendly communities and the relationship between the agency of individual dementia activists and the macro-social movement of dementia.

Personal reflection

This study evolved dramatically over time. My original application for the Graduate Teaching Assistant scholarship proposed a mixed-methods study of the carers of people with young onset dementia involving qualitative interviews and standardised measurement tools of stress and depression. My supervisors soon suggested that to exclude young people with dementia from the study would be to negatively position them within the research process, perpetuating their status as a marginalised group. I had had no previous experience with people with dementia, and even though it is somewhat embarrassing to admit it now, I was unsure how well they would be able to participate in interviews. I endeavoured to sensitise myself to the field and went to local dementia groups, discovering, of course, that many people living with dementia are extremely capable of expressing themselves. Nevertheless, I felt daunted when arriving for my first interview at each of the houses, wondering whether I would have the necessary sensitivity and empathy to conduct interviews without causing distress.

Undertaking this study after so many years of being at home has been a truly remarkable experience. My curiosity about the social world had never been dormant, but my intellectual understanding needed to be reawakened. Conducting this study has renewed my respect for the discipline of sociology, my desire for knowledge and my commitment to conduct research which can have a positive impact on people's lives. Findings are

currently being communicated to the dementia charities involved in the work and I have recently received feedback from the service manager at one of the organisations who has informed me that they are now prioritising the engagement of children and young people. We will continue to work together with the aim of improving services and are planning to co-author a paper later this year for the *Journal of Dementia Care* to outline the ways in which this research will shape their practice.

In addition, I am committed to contributing to the development of qualitative longitudinal methodology and have recently had a blog post published by the Economic Social and Research Council's National Centre for Research Methods on their QL website (<http://bigqlr.ncrm.ac.uk/2016/08/01/guest-post-5-sue-bellass-the-challenges-of-multiple-perspectival-ql-analysis/>). A copy of this post can be located in Appendix L. I also look forward to presenting my work at the British Sociological Association MedSoc conference in September 2016.

Developing an awareness that I have a contribution to make both to academia and to practice most clearly demonstrates to me the distance I have travelled since embarking on this PhD in 2012. As none of this would have been possible without the generosity of my participants, I would like, as this thesis reaches its conclusion, to leave the final words to Lauren, who offers an important message to us all:

Sue: *Do you think your outlook has changed has changed since your nana's diagnosis?*

Lauren: *Well it's taught me not to judge people*

Sue: *Not to judge people?*

Lauren: *Yeah 'cause you don't know what's going on in someone's life or what's happened to someone or what they're feeling inside so it's taught you to like ... to get to know people before you just go 'I don't like you' or 'they're mad, them' it makes you more ... aware before you say or do things ...I'd hate anyone to do that about my nana so I suppose it works both ways, if you know what I mean, if I don't want people to do that to my nana I shouldn't do that to other people.*

Appendix A: Literature Search Strategy

Databases used: ASSIA, MEDLINE, CINAHL, PsycInfo

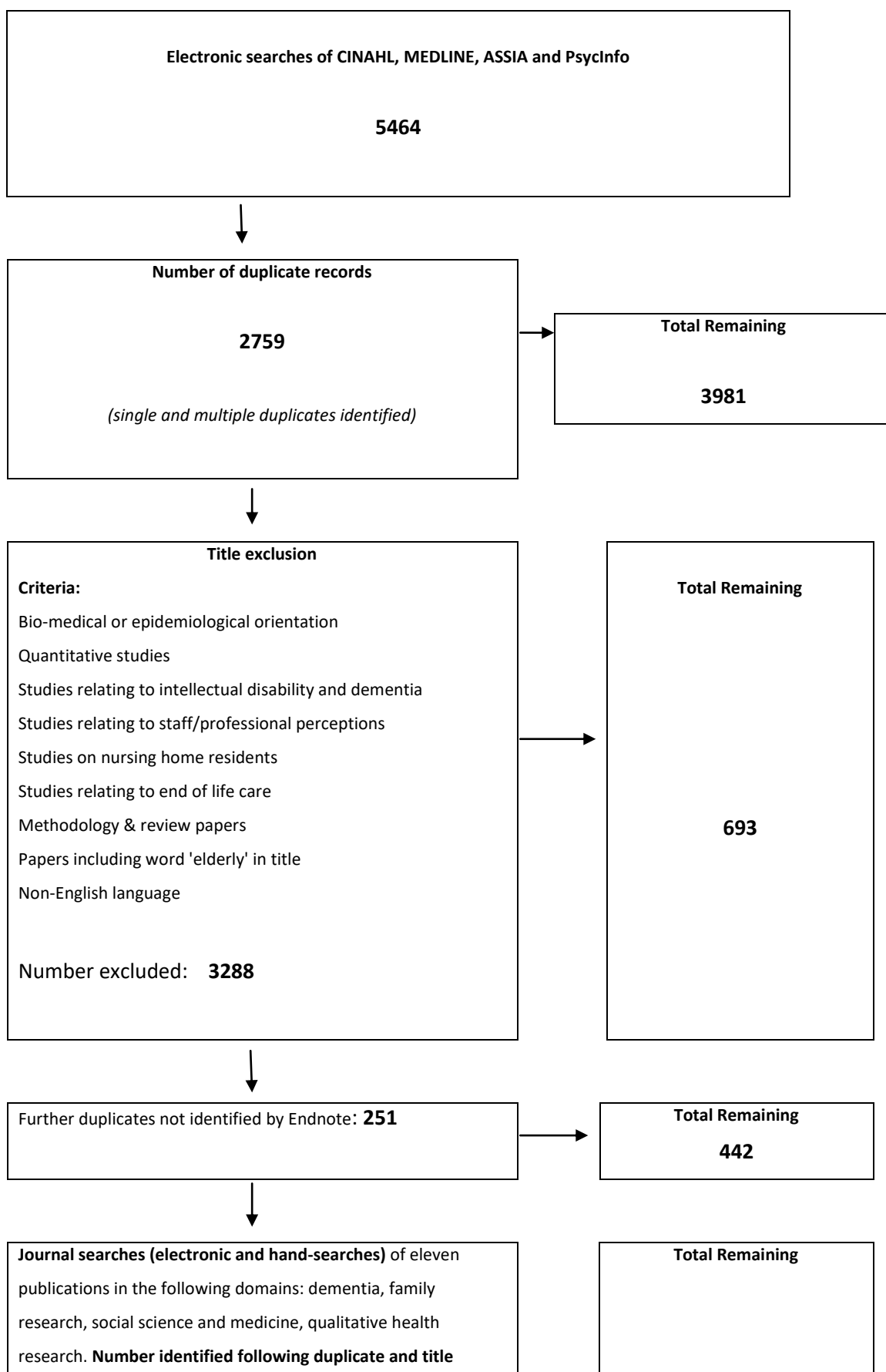
Key concept	Search terms used
Dementia Search terms identified using MeSH	AIDS Dementia Complex, Alzheimer* Disease, Aphasia, Primary Progressive, Primary Progressive Nonfluent Aphasia, Creutzfeld-Jakob Syndrome, CADASIL, Dementia, Multi-Infarct Diffuse Neurofibrillary tangles with Calcification, Frontotemporal Lobar Degeneration, Frontotemporal dementia, Primary Progressive Nonfluent Aphasia, Huntingto* Disease, Kluver-Bucy Syndrome Lewy Body Disease, Pick Disease of the Brain, Infarction - Anterior Cerebral Artery, Infarction - Middle Cerebral Artery, Infarction - Posterior Cerebral Artery, Tauopathies, Parkinso* Disease, Creutzfeldt-Jakob Syndrome Gerstmann-Straussler-Scheinker Disease, Kuru
Age of onset	Youn* onset, Youn* people, Earl* onset, Middle ag*, Working age, Presenile, Pre-senile, Under 65*, Young adult, Pre-retirement Age filters used on MEDLINE & CINAHL: Adult 19-44 years, Middle Aged: 45-64 years Age filters used on PsycInfo: Young Adulthood <age 18 to 29 yrs>, Thirties <age 30 to 39 yrs>, Middle Age <age 40-64 yrs>
Qualitative research	Qualitative, Phenomenology, IPA, Interpretative Phenomenological Analysis, Grounded theory, Ethnography, Ethnomethodology, Narrative Life course, Longitudinal, Action research, Case study
Family and Friendships	Family, Familial, Family relations, Kin, Intergenerational, Inter-generational, Children, Adult children, Adolescents, Teenagers, Relatives, Relations Siblings, Brothers, Sisters, Spouse, Husband, Wife, Parents, Mothers, Fathers, Grandparents, Grandmothers, Grandfathers, Extended family, Carers, Caregivers, Friends, Friendships, Personal relationships, Companion, Confidant

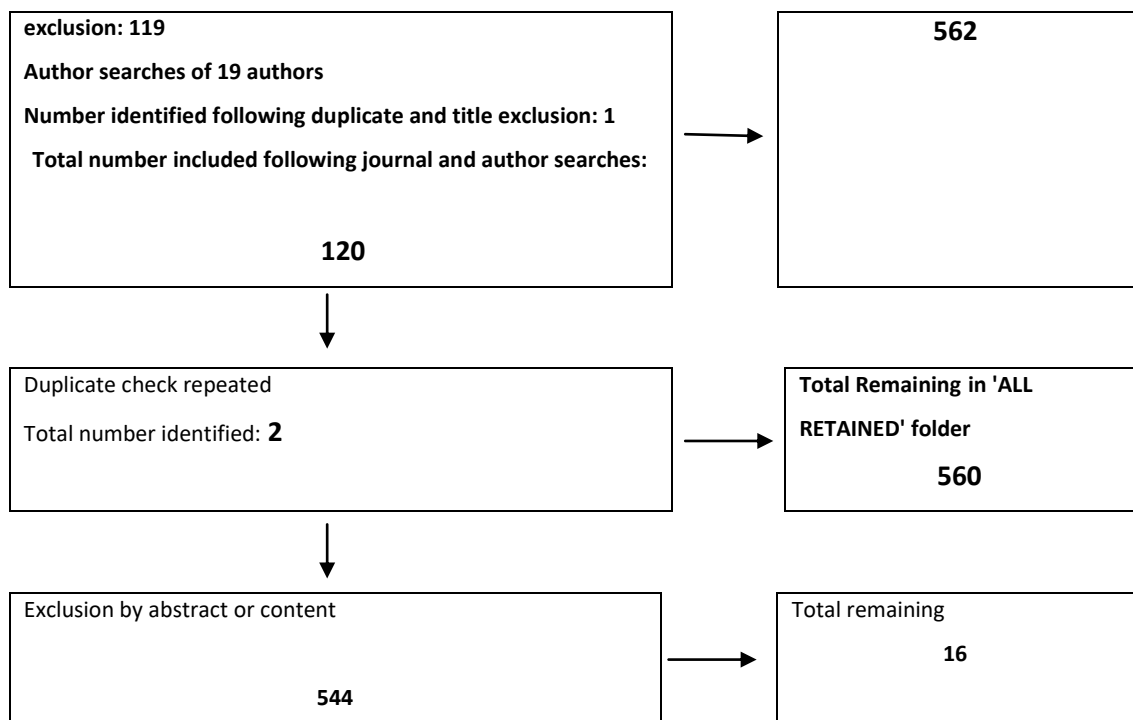
Journal and author search - summary table

Journal searches - electronic searches using keywords	Number retained following title exclusion/ duplicates
Cambridge journals online:	
International psychogeriatrics and Ageing & Society	34
Dementia	30
Journal of Advanced Nursing	5
Social Science and Medicine	5
Total retained from electronic searches of journals	74
Journal searches - handsearching	
Aging and Mental Health 1997-present	15
American Journal of Alzheimer's disease and other dementias 1986-present	17
Journal of Family Issues	1
Journal of Family Nursing	3
Journal of Family Studies	0
Qualitative Health Research	9
Total retained from handsearches	45
Total retained from journal searching	119

Author search using SOLAR	Number retained following title & duplicate exclusion
J. Oyebode, J. Keady, P. Roach, J. Millenaar, C. Bakker, M. de Vugt, D. van Vliet, M. Vernooij-Dassen, J. Kindell, J. Lafontaine, P. Harris, A. Beattie, S. Lockeridge, E. Svanberg, K. Klink, P. Panegyres, S. Kaiser, F. Pipon-Young, J. Reed.	1

PRISMA flow chart - literature search





One more relevant paper was discovered during a later re-run of the literature search, and a further identified via a Zetoc alert, bringing the total included in the review to **18 papers**.

Appendix B : Summary Of Studies In The Literature Review

Qualitative studies of people with young onset dementia							
Year	Author/ journal	Country	Design	Sample size	Aim	Method	Key findings
2004	Beattie, Daker-White, Gilliard & Means <i>Health and Social Care in the Community</i>	UK	Cross-sectional Individual interviews	14	General views of how dementia impacted on their lives and specific views about needs and services.	Part of a larger mixed method study. The qualitative element was conducted using the principles of grounded theory.	Frustration at other people's reactions and desire to be treated as an ordinary individual; rejection of services designed for older people; tensions between professional perceptions of risk and danger and individual's desire for independence.
2004	Harris <i>Social Work in Mental Health</i>	USA	Cross-sectional Focus groups, face to face, telephone and online interviews	23	To understand whether being diagnosed with young onset dementia is a unique experience and whether specialist guidelines and services are necessary.	Grounded theory (Glaser & Strauss)	Difficulty obtaining diagnosis; negative effect on selfhood and self esteem; changes to family roles; social isolation; lack of meaningful occupation; work and retirement issues.
2011	Johannessen & Möller <i>Dementia</i>	Norway	Cross-sectional Individual interviews	20	To gain insight into how people experience living with early onset dementia and to assess the implications for services	Grounded theory (Corbin & Strauss)	Difficulties accepting diagnosis; loss of sense of social cohesion; loss of friendships, ability to drive and work; experience of stigma; loss of confidence; minimal affect on family life and children; strengthening of spousal relationship.
2012	Pipon-Young, Lee, Jones & Guss <i>Dementia</i>	UK	Longitudinal Individual interviews and focus groups	8	To explore the experiences of younger people with dementia.	Action research.	Little discussion on employment, financial concerns or children; shock at age of diagnosis; non-disclosure and negative impact of others' perceptions of dementia

2014	Clemerson, Walsh & Isaac	UK	Cross-sectional Individual semi-structured interviews although some carers were present	8	To explore subjective experiences of young onset Alzheimer's Disease	Interpretative Phenomenological Analysis	Four superordinate themes emerged: disruption of the life cycle, identity, social orientation and agency
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Qualitative studies of children of people with young onset dementia

Year	Author/ journal	Country	Design	Sample size	Aim	Method	Key findings
2007	Forrest Keenan, Miedzybrodzka, van Teijlingen, McKee & Simpson <i>Clinical Genetics</i>	Scotland	Cross-sectional Individual interviews	33 (9-28 yrs, Mean 20.5 yrs)	To explore young people's experiences in families affected by Huntington's disease	Some elements of grounded theory, both Glaser & Strauss and Strauss & Corbin cited	Diverse experiences of growing up in a family affected by Huntington's disease; young people adopting caring roles; emotion-focussed and problem-focussed strategies
2009	Allen, Oyebode & Allen <i>Dementia</i>	UK	Cross-sectional	12 (13-24 yrs, mean 19)	To explore how psychological and emotional well-being of children is affected by having a father with young onset dementia	Grounded theory (Glaser & Strauss)	Fear of unpredictable future; strain; reconfiguration of relationships; psychological and emotional stress and family tensions
2010	Svanberg, Stott & Spector <i>Aging & Mental Health</i>	UK	Cross-sectional Individual interviews and	12 (11-17 yrs, mean 14.6)	To discover whether young carers of a parent with early onset dementia can be compared to other young carers	Grounded theory	Young carers found to be comparable to other young carers in tasks and outcomes; positive outcomes were increased maturity; negative outcomes were

			three psychometric measures				adverse effect on social life and education
2013	Millenaar, van Vliet, Bakker, Vernooij-Dassen, Koopmans, Verhey & de Vugt <i>International Psychogeriatrics</i>	Netherlands	Cross sectional Individual interviews	14 (15-27 yrs, mean 21)	To explore the experience of children living with a parent with young onset dementia	Generic qualitative	Changing family relationships; difficulties balancing responsibilities with their own life; coping strategies; need for help and support from services
2014	Barca, Thorsen, Engedal, Haugen & Johannessen <i>International Psychogeriatrics</i>	Norway	Cross sectional Individual semi-structured interviews	14 (20-37, no mean given)	To explore adult children's experiences of the development of their parents' young onset dementia	Modified grounded theory (Corbin & Strauss)	Participants experienced neglect by health and social care system. Increased family conflict, length of time living with the parent increased burden and stress.
2014	Hutchinson, Roberts, Kurrle & Daly <i>Dementia</i>	Australia	Cross sectional Individual interviews	12 (10-33 yrs, mean 24)	To explore lived experience of young people with a parent with young onset dementia from the perspective of the social model of disability	Generic qualitative	Society compounds problems faced by young people with parents with young onset dementia through exclusion and discrimination

Qualitative studies of carers of people with young onset dementia							
Year	Author/ journal	Country	Design	Sample size	Aim	Method	Key findings
2009	Harris & Keady <i>Aging & Mental Health</i>	USA/UK, data described here is from UK carers	Cross-sectional Individual interviews	15	To explore meaning, selfhood and identity	Grounded theory (Glaser & Strauss)	Transition in selfhood following diagnosis or awareness of first symptoms; identity as worker, sexual and social being affected by young onset dementia; narratives of loss and fear

2010	Bakker, de Vugt, Vernooij-Dassen, van Vliet, Verhey & Koopmans <i>American Journal of Alzheimer's Disease and Other Dementias</i>	Netherlands	Longitudinal Data collection at 0 and 12m	1	To explore experiences of carer during transition to residential care	Case study	Decision-making process stressful; fit between needs and services a key concern; complex issues related to work and finances; needs changed as disease progressed
2012	Lockeridge & Simpson <i>Dementia</i>	UK	Cross sectional Individual interviews	6	To explore carers' coping strategies when faced with young onset dementia	Interpretative Phenomenological Analysis	Combination of emotion-focussed and problem-focussed strategies adopted; emotion-focussed coping strategies led to conflict in some carers' relationships; stigma; fears for the future
2013	Oyebode, Bradley & Allen <i>Qualitative Health Research</i>	UK	Cross sectional Individual interviews	6	To understand how relatives of people with frontal-variant FTD* experience the illness	Interpretative Phenomenological Analysis	Social embarrassment caused by unusual behaviours of person with FTD; structural stigma; sense of losing the person
2013	Ducharme, Kergoat, Antoine, Pasquier & Coulombe <i>American Journal of Alzheimer's Disease and Other Dementias</i>	Canada	Cross sectional Individual interviews	12	To document the lived experience of spouse caregivers of young people with dementia	Informed by the principles of phenomenology	Quest for a diagnosis, managing challenging behaviours and adjustments to changing roles in family life impact caregivers' trajectory
2013	Flynn & Mulcahy <i>British Journal of Community Nursing</i>	Ireland	Cross sectional Individual interviews	7	To explore care-giving from the perspective of a family member	Descriptive qualitative methodology	Diagnostic problems; relationship change; social isolation and exclusion

* Frontotemporal dementia.

Qualitative studies of families with young onset dementia							
Year	Author/ journal	Country	Design	Sample size	Aim	Method	Key findings
2013	Roach, Keady, Bee & Williams <i>Ageing & Society</i>	UK	Longitudinal 12-15m Individual interviews	5 family constructions (13 participants)	To gain in-depth understanding of day-to-day experience of young onset dementia in the context of a family	Narrative co- construction of family biographies	Identified five constructed family storylines; dynamic relationship between experience of chronic condition and family functioning

Appendix C: Information Sheets

1. Information sheet for younger person with dementia (folded as a leaflet)



AN INVITATION TO TAKE PART IN A PROJECT



My name is Sue Bellass and I am inviting you to take part in a project. I'm a student at Salford University and I'm conducting this research to understand what it's like to live with dementia and about what kinds of things can help. I'm asking you to be a part of my project so I can learn about your experiences, thoughts, and feelings. Your views on how people with dementia can best be supported are really important.

I'd like to interview you three times over a nine-month period. I would expect these interviews to take up to an hour each. I'm also planning group discussions about the project at the end of twelve months which you would be invited to. For the individual interviews we can meet in your home or somewhere else that is private if you prefer. If you don't mind I'd like to audio record our conversations.

I'd like to offer you a range of other activities. If you'd like to write a diary or blog, that would be really welcome. Texting, taking photos and drawings are also very welcome. You can choose whatever you prefer.

It's important that you know that this project may not change your situation but what I learn from it could help other people and their families in the future.

It's up to you if you want to take part in this project. If you decide to say yes you will be asked to sign a consent form. If you change your mind you can bring your involvement to an end whenever you wish.

Everything we discuss will be kept private. I will share project findings with my supervisors at the university and will write reports in the future but your name and personal details will be kept private. The audio recordings will be stored in a locked safe place at the university, and will not have your name attached to them.

I'd also like to ask you to invite family members and friends to be interviewed for the project, or to contribute in other ways such as those mentioned earlier if they prefer. The more we can learn about how dementia affects people and their families and friends, the more we can work out what kinds of things can be put in place to help in the future.

During the year this project is expected to last I would hope to see you four times. In the event that your ability to be involved is affected by your dementia, and you cannot complete the research, you should consider whether the thoughts and feelings you have expressed can still be used in the project.

Please contact me if you have any questions. I am only too happy to discuss the project with you so please do not hesitate to get in touch.

s.bellass@edu.salford.ac.uk



2. Information sheet for 5-10 year olds



WOULD YOU LIKE TO TAKE PART IN A PROJECT?



My name is Sue and I am a student at Salford University. I am doing a project to learn about what happens when someone in your family has dementia. I am asking you to be part of my project so you can tell me what it is like. I want to understand how children like you and their families could be helped.

What will you do if you take part?

I will come and see you three times in 9 months to talk to you about your thoughts and feelings. If you want you can also write a diary or blog and send it to me. If you don't mind I will record our talks. That is because I don't want to miss anything you say. If you want to take part I will ask you and your parent or guardian to sign a form to say OK. A grown-up can be with you when we meet if you want.

What's good about this project?

What's good is that you can have your say and tell me what things are like for you. This project may not make things better for you but may help children like you and their families in the future.

What things might bother you?

Sometimes you might want to take a break. We will talk about ways you can tell me you would like to stop for a bit. You might feel sad if something you talk about upsets you. You only have to talk about things that you want to. If you don't want to answer a question you don't have to. We will decide ways you can tell me when you don't want to answer something.

Who else will I tell about what you say?

I will only talk about things you've said with my supervisors (they are like teachers at school) and in project

reports but your name will be kept secret so no-one knows you said it. The only way I would tell someone what you said is if something you say worries me about your safety or someone else's safety. Then I would have to tell my supervisors. This is to keep you safe. I would talk to you about this before I spoke to someone else.

Do you want to take part? It's UP TO YOU!

You don't have to be in the project. It's up to you to say **YES** or **NO**. No-one will be cross if you say NO. If you say YES but then change your mind that is **OK**. We can stop whenever you want.

Time to think....

Take time to think about what you want to do. Speak to people who care about you to help you decide whether to say **YES** or **NO**.

Please ask me any questions you like, or ask your parents to ask me questions.

This is me



This is my email address: s.bellass@edu.salford.ac.uk

3. Information sheet for 11-16 year olds



AN INVITATION TO TAKE PART IN A PROJECT



Who I am and what I'm doing...

Hi, my name is Sue and I am inviting you to take part in a project. I'm a student at Salford University and I am doing this study to understand what it's like to have a family member with dementia. I'm asking you to be a part of my project so I can find out about your experiences, thoughts, and feelings, and about what could help young people like you.

Some questions you may have...

What are you asking me to do?

I'd like to interview you three times over a nine-month period for about half an hour a time. I am planning group discussions about the project at the end of twelve months which you would be invited to. We can meet in your home or somewhere else that is private if you prefer. You can have someone with you if you wish. If you don't mind I'd like to audio record our conversation so that I don't miss anything. You can decide not to answer any questions that you don't want to. An adult can be with you when we meet if you like.

I'd like to offer you a range of other activities. If you want to write a diary or blog, you are very welcome to do that as well. Texting, taking photos and drawings are also very welcome. You can choose whatever feels best to you.

Why should I take part?

It's important that you know that this project may not change your situation but what I learn from it could help other young people and their families in the future.

Can I decide myself or will someone else decide for me?

It's up to you if you want to take part in this project. No-one will be annoyed if you don't want to be involved. If you do agree and later change your mind you can stop at any time. If you decide to say yes you and your parent or guardian will be asked to sign a consent form.

Will other people be told what I say?

Everything we discuss will be kept private. I will share what I learn from the project with my supervisors at the university and will write a report in the future but your name and personal details will be kept private. If you like you can choose a different name. The only time I would need to tell anyone your real name is if something you said made me concerned about your safety or someone else's safety. We would discuss this together before I talked to anyone else.

What if I need more information to help me decide?

You can ask me as many questions as you like to help you make a decision. My contact details are below. Take some time to think about it and talk to your friends and family too. It's completely up to you if you want to take part or not -**you decide!**



My email address is s.bellass@edu.salford.ac.uk

4. Information sheet for adult family and friends



AN INVITATION TO TAKE PART IN A PROJECT



My name is Sue Bellass and I am inviting you to take part in a project. I'm a student at Salford University and I'm conducting this research to understand what it's like to have a relative or friend with dementia and about what kinds of things can help. I'm asking you to be a part of my project so I can learn about your experiences, thoughts, and feelings. Your views on how people with dementia can best be supported are really important.

I'd like to interview you three times over a nine-month period. I would expect these interviews to take up to an hour each. I'm also planning group discussions about the project at the end of twelve months which you would be invited to. For the individual interviews we can meet in your home or somewhere else that is private if you prefer. If you don't mind I'd like to audio record our conversations.

I'd like to offer you a range of other activities. If you'd like to write a diary or blog to send your thoughts to me you are very welcome to do that as well. Texting, taking photos and drawings are also very welcome. You can choose whatever you prefer.

It's important that you know that this project may not change anything for you but what I learn from it could help other people and their families in the future.

It's up to you if you want to take part in this project. If you decide to say yes you will be asked to sign a consent form. If you change your mind you can bring your involvement to an end whenever you wish.

Everything we discuss will be kept private. I will share project findings with my supervisors at the university and will write reports in the future but your name and

personal details will be kept private. The audio recordings will be stored in a locked safe place at the university, and will not have your name attached to them.

The more we can learn about how dementia affects people and their families and friends, the more we can work out what kinds of things can be put in place to help in the future. If there is anyone else you feel may like to contribute to the project you are very welcome to invite them to participate.

Please contact me if you have any questions. I am only too happy to discuss the project with you so please do not hesitate to get in touch.



Email address: s.bellass@edu.salford.ac.uk

Appendix D: Consent Forms

1. Consent form for young person with dementia

CONSENT FORM

PART A

I agree to take part in the study on dementia. I would like to:

- ☐ Take part in interviews
- ☐ Create a diary
- ☐ Use a blog and/or text to share thoughts with the researcher
(please complete Part B overleaf)

I have read and understood the information leaflet. I am aware that I don't have to answer any questions that I don't want to and that I can stop being part of the study whenever I choose.

I know that what I say will be used by the researcher to write reports or develop teaching materials but that my name or any other identifying details will NOT appear on anything that is produced.

In the event that my ability to complete all stages of the research is affected by my dementia, I agree that my earlier contributions to the project can still be used.

☐ Yes

☐ No

I am happy for the interviews to be audio-recorded (please tick one of the boxes) and understand that the researcher will comply with the Data Protection Act (1998) to ensure data security.

☐ Yes

☐ No

Name _____

Signature _____

PART B

I confirm that I have received information from the researcher about creating a private blog on the project website. I am aware that the blog would be read by Sue and her supervisory team.

Name _____

Signature _____

2. Consent form for 5-10 year olds

CONSENT FORM [5-10 yrs]

TO BE COMPLETED BY CHILD AND PARENT/GUARDIAN

PART A TO BE COMPLETED BY CHILD

I agree to take part in the study on dementia. I would like to:

☐ Take part in interviews

☐ Write a diary or blog  Go to **Part C!**

I have read and understood the information leaflet. I know what the study is about. I know that I don't have to answer any questions that I don't want to. I know that I can stop being part of the study whenever I want to.

I know that Sue will write reports that might include things I've said. I know that she will not use my name on anything she writes. I am happy for Sue to audio-record our interviews (it's up to you! Please tick a box below to tell me what you think):

☐ Yes

☐ No

Name _____

Signature _____

Age _____

PART B TO BE COMPLETED BY PARENT/GUARDIAN

I have read and understood the information leaflet and give permission for the child (named above) to be included in the study.

Name _____

Relationship to child _____

Signature _____

PART C

I confirm that I have received information from Sue about creating a private blog on the project website. I know the blog would be read by Sue and her supervisors.

Name _____

Signature _____

TO BE COMPLETED BY PARENT/ GUARDIAN

I confirm that I allow my child to create a private blog on the project website. I have been provided with information about the security of the blog. I am aware that the blog would be read by the researcher and her supervisory team.

Name _____

Relationship to child _____

Signature _____

3. Consent form for 11-16 year olds

CONSENT FORM [11-16 years]

PART A TO BE COMPLETED BY YOUNG PERSON

I agree to take part in the study on dementia. I would like to:

- ☐ Take part in interviews
- ☐ Create a diary
- ☐ Use a blog and/or texts to share thoughts with the researcher
(please complete Part C overleaf)

I have read and understood the information leaflet. I know why the study is being conducted. I know that I don't have to answer any questions that I don't want to and that I can stop being part of the study whenever I choose.

I know that what I say will be used by the researcher to write reports or develop teaching materials but that my name or any other identifying details will NOT appear on anything that is produced. I am happy for the researcher to audio-record our interviews (please tick one of the boxes) and understand that the researcher will comply with the Data Protection Act (1998) to ensure data security.

- ☐ Yes
- ☐ No

Name _____

Signature _____

Age _____

PART B TO BE COMPLETED BY PARENT/GUARDIAN

I have read and understood the information leaflet and give permission for the young person (named above) to be included in the study.

Name _____

Relationship to young person _____

Signature _____

PART C

I confirm that I have received information from the researcher about creating a private blog on the project website. I am aware that the blog would be read by Sue and her supervisors.

Name _____

Signature _____

TO BE COMPLETED BY PARENT/ GUARDIAN

I confirm that I allow the young person named above to create a private blog on the project website. I have been provided with information about the security of the blog. I am aware that the blog would be read by the researcher and her supervisory team.

Name _____

Relationship to young person _____

Signature _____

4. Consent form for adult family members and friends

CONSENT FORM [adult family member/friend]

PART A

I agree to take part in the study on dementia. I would like to:

- ☐ Take part in interviews
- ☐ Create a diary
- ☐ Use a blog and/or texts to share thoughts with the researcher
(please complete Part B below)

I have read and understood the information leaflet. I am aware that I don't have to answer any questions that I don't want to and that I can stop being part of the study whenever I choose.

I know that what I say will be used by the researcher to write reports or develop teaching materials but that my name or any other identifying details will NOT appear on anything that is produced.

I am happy for the interviews to be audio-recorded (please tick one of the boxes) and understand that the researcher will comply with the Data Protection Act (1998) to ensure data security.

- ☐ Yes
- ☐ No

Name _____

Signature _____

PART B

I confirm that I have received information from the researcher about creating a private blog on the project website. I am aware that the blog would be read by Sue and her supervisory team.

Name _____

Signature _____

Appendix E: Samples Of Wave Two And Wave Three Topic Guides (Family One)

1. Wave Two topic guide

a) Changes since first interview/ recent experiences of the effects of dementia on daily life

b) Self and Identity

How they make sense of dementia; others influence the experience of living with dementia; refer back to wave one theme of emerging activism and understand motivations; understand more about persistence of professional identity; important things they can't do because of dementia

c) Temporality

Explore whether they experience 'good days' and 'bad days' like other participants, if so, understand what distinguishes a 'good day' from a 'bad day'; understand what kinds of things help in their daily life; refer back to the turning points mentioned in wave one and explore whether there have been other significant moments in their experience; develop theme from first interview about the importance of routine, understand whether it has changed and how it helps; explore goals for the future

d) Relationality

Refer back to their perception of family relationships in wave one, ask for more details about the ways in which family and friends are (un)supportive; develop understandings of how they prefer people to behave towards them; explore how family members make sense of the dementia; understand more about the effect on friendships; refer back to perception that grandchildren (with the exception of Lauren) did not understand dementia and probe for changes/continuities; experiences of recent disclosures

e) Dementia & society

Understand views of the increasing public focus on dementia, understand their perceptions of how dementia is viewed socially; probe for experiences with members of the public; understand perceptions of how communities might be more sensitive to people with dementia

f) Formal support/ information

Perceptions of support/ treatment received at the hospital, understand how people with dementia and their families could be better supported; understand perceptions of information received/ sought about Alzheimer's Disease; perceptions of support from dementia charity/ support groups/ other agencies

g) Final questions

Is there anything else that we haven't talked about that you'd like to discuss? What is most important to you at the moment?

h) Reflections

Understand perceptions of involvement in first interview and in project in general

2. Wave Three topic guide (Family One)

a) Changes since second wave interview/recent experiences of the effects of dementia on daily life

b) Self and identity

Refer back to diagnosis being perceived as both a shock and a relief, probe for further details; explore what having dementia means now; discuss issues raised previously of word-finding difficulties, explore changes/continuities; explore perceptions of others' views; develop conversation about activist/ fundraising/ educational activities; understand what helps to manage the condition

c) Temporality

Discuss the trajectory over the year and ask for reflections; explore whether there have been any turning points in the recent experience of dementia; encourage reflections on the past and hopes/ goals for the future; refer back to previous discussions of making the most of the present, explore changes, continuities; refer back to previous discussions of normalisation, explore changes, continuities

d) Relationality

Refer back to previous discussions of support from close family members; refer back to friendships and explore changes and continuities; explore the relevance/ usefulness of humour; refer back to perceptions of grandchildren's awareness, explore changes and continuities; explore experiences of recent disclosures

e) Dementia & society

Explore perceptions of social attitudes towards dementia, including media portrayals of dementia; explore recent experiences with members of the public; explore perceptions of social changes that could benefit people with dementia

f) Formal support and information

Recent experiences of hospital support and how support could be improved; perceptions of support from dementia charity/ support groups;

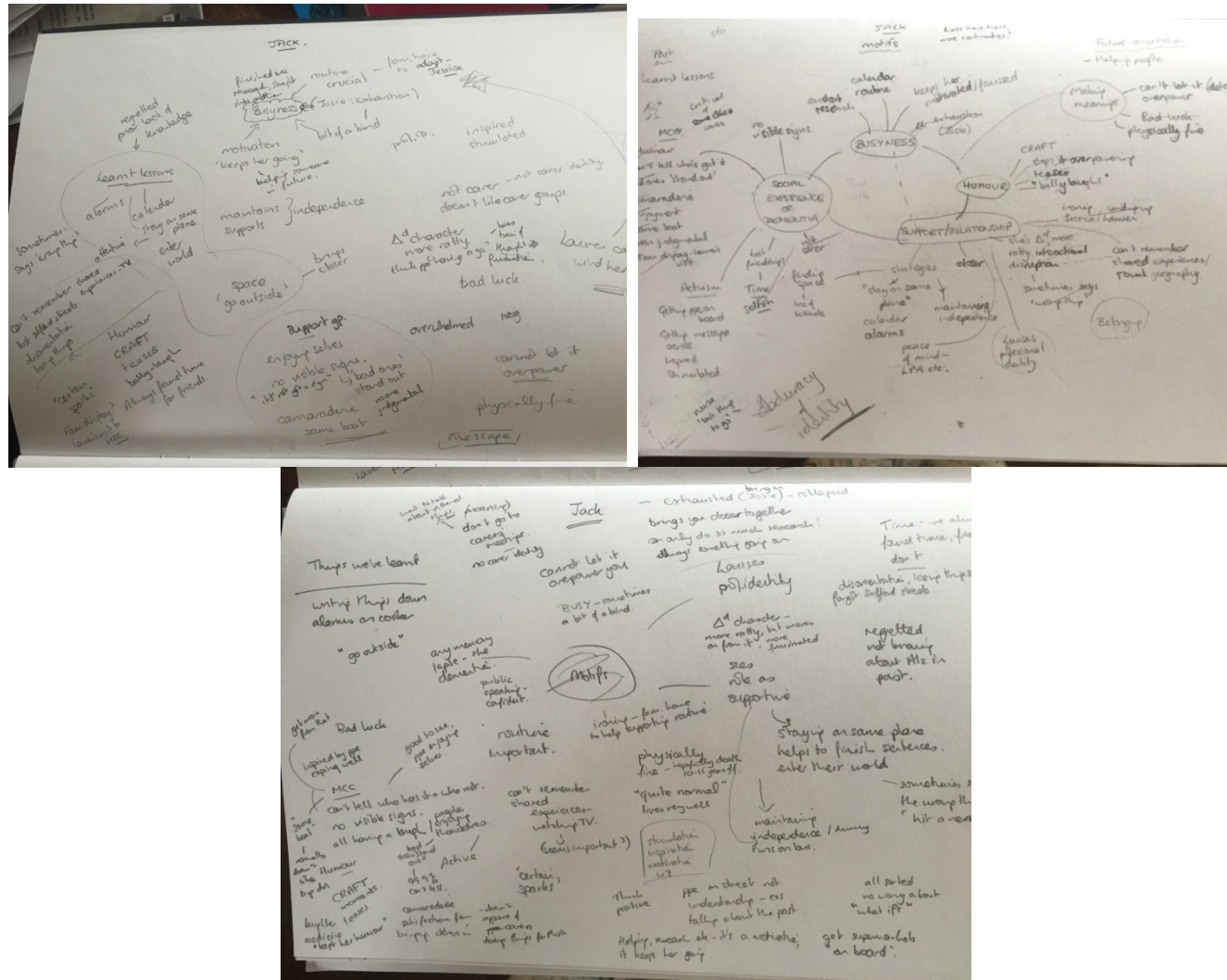
g) Final questions

Is there anything else that we haven't talked about that you'd like to discuss? What is most important to you at the moment?

h) Reflections

Review their perceptions of their involvement in previous interviews and in project in general; ask what messages they would give to other families going through a similar experience

Appendix F: Example Of Mind Maps (Jack, Family One)



Appendix G: Excerpt From A Time-Ordered Matrix (Julia, Family 2)

	Wave One	Wave Two	Wave Three
Relationships: parents	<p>I couldn't even find the words to tell them 'cause they're both in their late 80s and even when I ... but then it was making me ill towards the time...they've only just... probably in the last 6 months or so told them and of course my mother's still ... she just don't believe it, she just thinks it my eyes. I said 'it's not my eyes there's nothing wrong with my eyes, mother' I said 'it's my brain' 'oh well I don't know about that' she just don't accept it... and then of course she was a bit annoyed because they weren't told when everybody else was, but it's just because it's still quite raw, and just couldn't say it to them, I was just, you know, but I thought 'how am I going to tell my mother and father at that age that I've got dementia?' and erm it was very hard anyway because it was making me ill... I was literally every night I'd go to bed and I'd try and find the words to tell them without shocking them and erm of course because a few people knew it we were worried that somebody would walk around in the centre there and say 'erm shame about your Julia, isn't it?' or, do you know what I mean, and they wouldn't know, erm, yeah so that was it really me and my mother, I've fallen out with her for about four years before that</p> <p>And the problem is now, is, she's as nice as pie and everything and I said to Peter, 'why couldn't she have been like that all the years? or the son-in-laws or all them, they're just rubbish, never good enough</p> <p>it was just sort of trying to sort of like ease it for my mother</p> <p>my mum and dad really aren't that, wasn't that huggy [Peter : Loving towards her, even when she was small] even when I was little, I could never... we had everything, you know, physically, we had everything but we never had really big hugs and stuff like that. It was more about, like when we had birthday...birthdays, because my brother and I are really close, and erm of course we had a great</p>	<p>We went down there and I didn't even think about it really, but Peter come back and he says 'do you know, you looked really lovely yesterday' not like, I mean I always do anyway but yeah, he said 'your mother never even said how nice you were dressed and stuff, but I wouldn't even think of something like that but no, it's difficult, it's very difficult, and Peter says, 'cause Peter'll say 'oh shall we go down to your mother's?' and my shoulders they just drop</p> <p>It's the son-in-law and mother-in-law thing she's just a hard hard person that's all, and if she wants to say something, I mean, she's in her eighties, I think she's coming down with it (dementia) 'cause the other day, something about erm we were going (to Peter) where were we going? [Peter: We were going to that meeting, and your mother said] and my mother said [Peter: 'What do you want to go there for?'], she said, (<i>in sharp tone</i>) 'what do you want to go there for?' and that's, that's the tone she will give you and I said 'well because we go and see all our friends and we find out things about everything' No, they don't accept it. They're mortified that everybody who is anybody knows she don't even, she don't even rate them (Colin & Celeste) because they're so good to us, so it's like a jealousy, do you know what I mean, and they, she can't even bring herself to call my friend Celeste which is her name</p> <p>they're as tight as this (<i>clenches hand</i>) in the household, nothing goes up, nothing goes out, nothing comes in, do you know what I mean, and they, they, they live in [Peter: In their own cocoon] yeah, no, they live in a ...where you get to the end of it [Peter: Cul-de-sac] cul-de-sac and they're forever like that (<i>mimes peeping from behind curtains</i>) 'ooh look at him, who's he going down the road with?' And this is while we're in the bloody room! They don't make any conversation, my dad only sits there and watches the television</p>	<p>My Dad said straight away 'well I'd like to come down but your mother's come down with a' ... she had a bit of a ... Funny turn</p> <p>But my Dad... my Dad said he would come, but erm he said 'I can't leave your mother, I don't want to leave your mother'... But they're as fit as fleas! No, we always had, we always had, the best clothes, the best shoes, but there was not much loving there, do you know what I mean? I'd have rather not had all the frocks and stuff do you know what I mean? But there you go.</p> <p>Who knows and when... 'who's gonna look after us J?' That's what they said. There you go. But we do go up there but not so much, I mean we're only down the road, but you just got to... it's like, when my Dad said... I said 'well maybe she's just got a cold or something like that' and he said 'well you know what your mother's like' and I think in my mind, 'cause then I get... it makes me a bit depressed, so when we go there, and they say something that's not good, I say 'we're going now, we're going now, Peter' you know. Me mother'll say 'you're going a bit early' I say 'yeah yeah yeah we're going now' and I just get up and Peter knows now, 'cause he used to sort of like stay there a bit and I say, I've told him now, that when I say we're going [Peter: We're going, we go] we go.</p> <p>But I keep telling you I don't need to go down there!</p> <p>(People disapproving of not visiting parents) What people? Yeah but that's old-fashioned.</p> <p>I said, I said to Peter, I said, 'I'll murder you before I go down there to my mother and father' (laughs) really because she's... they're just ... even if we go there and visit them, we very rarely go there now, all they're interested in is looking out the window and seeing who's coming and who's going and who's coming... Oh God, do you know what I mean, that's their little world and they don't want to go anywhere, do you know what I mean? So</p>

	<p>big...everybody come and everything, it was all show and all the rest of it, when you look at it you can say that, do you know what I mean, and erm so it was quite difficult really.</p> <p>I hope she don't get a full-blown or anything, that wouldn't be good</p> <p>my Dad is sharp</p> <p>But then going back to my father, when I said, 'cause they said 'are you alright for money and all that' I said 'yeah' I said 'cause we can claim for this, and we can claim for that, and everything, and of course Peter had got his err allowance from the caring, didn't you? And then when I said to my parents about it, when they said 'oh you know, are you alright for money and stuff' not that they would have given us any, 'cause they always say no, anyway, but, we've always been independent haven't we? And my dad said, he said 'um' he said, just like that, 'cause he doesn't talk much but when he does he comes out with it, he says well, he said 'there's too much of that going on, getting all this money from the, from the</p> <p>[Peter:government] oh I was so mad! Do you know what I mean? And I said to my dad, I said, 'don't you think that I would rather be getting up at 7 o'clock in the morning, all weathers, going into the shop that's always Goddamn cold, I'd rather be doing that, than have this, and then having this money' I'd rather go without</p>	<p>and it's not like, it's not like you're going there for anything really, it's just the fact that you feel as if you should pop in, but really, sometimes I think, I get the errr... I think they wouldn't be bothered whether we come or not that's what I think, you know</p> <p>my mother'll phone up and she'll say, 'are you coming?'... she phoned yesterday for something and I was really bad yesterday, I had a bad day yesterday, and I said to her, 'cause I do tell her now when I'm... and she says 'how are you our Julia?' and erm then I tell her I just give her the list that I'm having that day, and she says 'well why don't you come down to our house?' like as if Peter's not looking after me, you know what I mean, and I said 'no, mother, I'm staying at home I don't want to go anywhere, only stay at home' if you go to give him a... if I go to give him a cuddle, it's like as if it's...erm... he's gonna catch it!! he sort of like, he tenses up, so that's not very nice... they've never been right lovey</p> <p>So now what I do is, when my mother turns around and says something like, just calls Peter 'him' [Peter: She doesn't use my own name] I stood up, I said 'come on, Peter, we're going now' and my mother said 'why are you going you've only just got here' I said 'cause I don't want to listen to you saying, calling Peter him' [Peter: 'Is he going?', she'd say, that's what I mean, I did have a few rows with her, I have to bite my tongue] I mean but Peter is a bloody... well, he's not a saint 'cause we do row, but you know I don't need it from outside people.</p> <p>I think he does (accept the PCA) but he is a quiet man anyway, he's a very quiet man anyway she (sister-in-law) would have been a perfect daughter-in-law for my mother and father but no, only because she used to, she worked in a pub, and my brother likes to go and have a drink and you know, just because they don't like it, they're just hateful to people</p> <p>everybody who he went out with wasn't good enough. The only one that was good enough was this Italian young girl that was really really and</p>	<p>that... I had a bit of a stressy bessy this morning... it just, it just seemed as if me mother did it on... did it on ... you know...</p> <p>That's the first thing we've ever asked, yeah, yeah, I mean it's like...</p> <p>I think they're... well the thing is when they first said about it and blah de blah de blah, I said to them, 'well it's all about the genes, it's not my fault, it's the genes' and they argued between themselves</p> <p>I mean it's like the centre, just down the road, everybody can just sort of goes there, and you can see loads of people that you always know, and if I was there and my mother was there she would veer me away from anybody, do you know what I mean, so, and that's really pants. Yeah, 'cause I'm not, you know, I have got something wrong with me, but you know, I think I do quite well.</p> <p>They're ashamed, they're ashamed [Peter: That's it]. And they didn't like it when I said it was all about the genes. I mean I don't know whether it is or not, I don't know, but</p> <p>They won't come to the meets... Well they could come to the erm one where we're dancing and stuff, they could come to that, 'cause that's families...and that's lovely because there's grandchildren and children, and nice cakes</p>
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		<p>they had family, money, things like that, and they couldn't say the best of her</p> <p>12 hour days she (sister-in-law) does at the weekends, you know, what more do they bloody want?</p> <p>Because they don't to know, 'cause they don't want to believe I think, I think that's more what it is</p>	
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Appendix H: Sample Of Longitudinal Matrix (Francine, Family Three)

Person: Francine, person living with semantic dementia

Family: Three

Dates interviewed: Aug 2014-Feb 2015-Aug 2015

Emergence/ accretion	Decrease/ cessation	Continuities	Turning points/ fateful moments
<p>Increasing sorrow, crying episodes</p> <p>Increasing forgetfulness of meetings, appointments, names of objects</p> <p>Increasing physical problems, accidents, shaking, clumsiness, changing taste</p> <p>Displaying family photos in the home to jog/ preserve memories; looking at photo albums of past holidays and events</p> <p>Becoming a dog owner, perceiving that the dog will provide independence</p> <p>Increasing identity as person with dementia: only watches TV if programme about dementia, goes to slimming club because people with dementia can gain weight</p> <p>Becomes aware that Ron knows more about dementia than he told her</p> <p>Nervous in airports, on planes</p> <p>Worry that physical illness is something serious e.g. sore throat is throat cancer</p> <p>Transition from being nervous of new things to nervous of everything</p> <p>Increasing frustration and annoyance at not being able to remember things</p> <p>Started to check memory of road signs when driving</p> <p>Being encouraged by dementia charity to get involved in more activities</p> <p>Increasing awareness of deterioration of others at support groups; increasing comparison to others with dementia and fear that she will become like them; acute observations made of others' stages of dementia</p> <p>Developing friendship with a woman at support groups</p>	<p>Cooking - prepares food from packets</p> <p>Watching TV programmes with Ron, prefers to do Sudoku on tablet</p> <p>Perception that semantic dementia is rare - getting to know or hear about more people with the condition</p> <p>Confidence in driving</p> <p>Contact with eldest grandchild which she perceives as related to her age/ stage of development</p> <p>Stopped doing certain household tasks because of accidents which she attributes to dementia</p> <p>Desire to go abroad for long holidays</p> <p>Inability to work officially confirmed by Department for Work and Pensions</p> <p>Reduced sorting out of clothes</p> <p>Confidence at shopping for gifts for the family</p>	<p>Concern that migraine medication may have caused dementia</p> <p>Difficulties making decisions</p> <p>Forgetting people's names, and subsequent distress at forgetting names, frustration, embarrassment</p> <p>Continuing to play electronic games in belief that it helps her</p> <p>Distress at not being able to draw for grandchildren; drawing pictures for them seen as part of the way they relate to each other</p> <p>Friendships with former colleagues, meet in town</p> <p>Lack of confidence, fear of making mistakes socially</p> <p>Uncertainty whether dementia is causing her migraines & anxiety</p> <p>Hope that none of her children/ grandchildren develop dementia</p> <p>Helps that people know about her condition; if she does something wrong it is because of dementia</p> <p>Frustration that the cause of the dementia is not known</p> <p>Hope for a cure</p> <p>Writing things down, turning to Ron for reassurance</p> <p>Belief that it is good to do what doctors suggest</p> <p>Appreciation of support from dementia charity</p> <p>Appreciation of hospital support</p> <p>Awareness that family members don't tell her if she says something wrong</p> <p>Sons reminding her of aspects of their childhoods</p> <p>Appreciation of Ron and sons, acknowledgement of closeness</p> <p>Mother's lack of acceptance of the condition/ lack</p>	<p>Accidents around the home or in public</p> <p>Becoming a dog owner</p> <p>Getting angry/ frustrated at diminishing capabilities at work, dissonance with identity as popular, experience, competent manager</p> <p>Became unable to deal with IT at work</p> <p>Retiring reduced stress but misses the people</p> <p>Husband noticed her getting words wrong</p> <p>Relief that doctors do not connect her semantic dementia with granddaughter's brain condition</p> <p>Seeing her brain on the computer screen</p> <p>Relief at being diagnosed so had a rational explanation for problems</p> <p>Being asked to have the one-to-one service provided by the charity and refusing it on more than one occasion</p> <p>Preparing wills</p>

<p>Wanting sons to attend support groups with her</p> <p>Increasing/ more varied attendance at support groups & events</p> <p>Increasing worry that Ron will be unable to cope</p> <p>Increasing holidaying with friends</p> <p>Starting to spend time with dog rather than sort out clothes</p> <p>Perception that she could have stayed at work as a cleaner</p> <p>Developing concern with sons' inheritance of her mother's money if she dies first, wants to protect sons' inheritance</p> <p>Concern about others developing dementia who may attribute forgetfulness to old age</p>		<p>of recognition of limitations she experiences/ undermines her memory loss</p> <p>Mother's favouritism of younger sister</p> <p>Older grandchildren aware of dementia, told they have to be good, don't ask about it</p> <p>Troubled relationship with siblings, feels manipulated into looking after mother when it is convenient for them</p> <p>Diagnosis not repaired troubled relationship with younger sister</p> <p>Distress at forgetting things she wants to remember and remembering things she wants to forget</p> <p>Desire to keep active and keep as normal as possible</p> <p>Fear of brain getting smaller</p> <p>Worry about how long she will live</p> <p>Worry about not being able to drive in future</p> <p>People now more educated about dementia, more on TV</p>	
<p>Relationality/ intergenerationality: Maternal role: inability to choose to retain significant memories of sons affecting identity as mother; inability to draw affecting identity as grandmother; negotiated meanings of dementia, differential attribution of difficulties to dementia; enjoys sharing memories of family events that she can recall; troubled relationships with sisters and mother not improved by diagnosis; perceives relationship with sons/ daughters-in-law to be supportive but they don't express a desire to attend support groups; husband accompanies her to groups and appointments and they develop coping strategies together; fear of heritability; developing social identity of dementia</p>			
<p>Motifs: Lack of confidence, identity as competent employee challenged, retaining unpleasant memories, complies with medical advice</p>			
<p>Temporal themes: Recapturing past through use of photo albums, trying to remember holidays and other events; intensification of present, concerted time; fear of future realised through seeing others with more advanced dementia, concerns about Ron's ability to cope</p>			

Appendix I: Intergenerational Matrix

Generation/Theme	Making sense of dementia & trying to reduce impact on lives	Individual/ collective identities	Temporality	Relationality	Support Services	General public/ societal response to dementia
Parents				<p>Offers to look after Julia on a bad day, offer not accepted Violet F2</p> <p>Interested in materialism and social status not love & affection Julia F2</p> <p>Delayed telling parents about diagnosis Julia F2</p> <p>Disapproval of getting benefits. Julia F2</p> <p>Ashamed/ stigmatised; own parent had dementia, was a family secret Julia F2</p> <p>Jealous of help from beyond family Julia F2</p> <p>Chose not to participate in research? Violet & Jonathan F2</p> <p>Feels obligation to visit despite difficult relationship. Perceives himself not to be 'good enough'; lack of reciprocity. Reprioritised Peter F2</p>		

				<p>Mother doesn't seem to understand limits placed on her by dementia, expects too much Francine F3</p> <p>That side of family doesn't accept; mother starting to realise because of bad heads Ron F3</p> <p>Francine's mum doesn't understand, is selfish, thinks she has worse problems than Francine Laurence, David F3</p>		
People living with young onset dementia/ spouses/ friends/ other relations	<p>Cancer & other illnesses more visible Louise, Jack F1</p> <p>Passed off initial signs of dementia Louise F1</p> <p>Would have construed memory loss as normal part of ageing if retired; because of impact on work had to reconstruct experience Louise, Jack F1</p> <p>Role of fate in diagnosis - change in retirement age and problems at work led to seeking medical advice Louise, Jack F1</p> <p>Dementia could happen to anyone, even someone physically fit Louise F1</p> <p>Can't control future, no point worrying</p>	<p>Camaraderie at support groups Jack F1</p> <p>Becoming more active, campaigning for change Louise, Jack F1</p> <p>Pride at changing entrenched views towards dementia Louise F1</p> <p>Persistence of professional identity, perpetuated through friendships with former colleagues; past re-imagined in present Louise F1</p> <p>Importance of sharing memories from the past Louise, Josie F1</p> <p>Behaviour at work in stark contrast to identity as competent multi-tasker</p>	<p>Routine: asserting control, structuring time Louise, Jack F1</p> <p>Control aspects of the future that can be controlled, ignore those that can't, liberating the present Louise, Jack F1</p> <p>Don't want to see 'end result' Louise, Josie F1</p> <p>Unmedicated time 'lost time'; couldn't form sentences Louise, F1</p> <p>Louise's schedule tiring, taking its toll Jack, Josie F1</p> <p>Turning points: Losing ability to work & deserve salary, drive and manage</p>	<p>Josie spends time with Louise to give Jack respite Josie F1</p> <p>Disapproves of friends that have stopped contact - 'always made time for them', lack of reciprocity Jack F1</p> <p>Sudden reminders of dementia e.g. forgetting TV programmes, watching them again Jack F1</p> <p>Perceives Violet's offer of help as tacit criticism of Peter's support Julia F2</p> <p>Stress makes bad days worse; limited contact with parents Julia F2</p> <p>Forging new friendships at</p>	<p>Didn't want to engage with services for older people Louise F1</p> <p>Difficulties accessing age-appropriate services Louise F1</p> <p>Carers' support group inappropriate - focus on difficulties and on divide between carer and cared for Jack F1</p> <p>Humour as essential, shared family practice Jack F1</p> <p>Perception that hospital appointments not valuable Julia F2</p> <p>Hospital appointments refer to useful services</p>	<p>Stigma anticipated but people responded well; perceive her to be too young Louise F1</p> <p>Forgetting names of former colleagues distressing although they understand Francine F3</p> <p>Observed that Joan thinks she is a nuisance, gets bad reactions from general public because she's younger so they don't assume dementia Doreen F5</p>

	<p>Louise F1</p> <p>Brain 'jumbled up' losing words like 'lift doors closing' Louise, Jack F1</p> <p>Increasing physical fitness, desire to improve physical health (mitigates against unseen neurological degeneration?) Louise F1</p> <p>Normality - can't see difference between PWD and carers at support group Jack F1</p> <p>Developing dementia: bad luck Jack F1</p> <p>Need to maintain calm environment, manage other family members' behaviour Jack F1</p> <p>Dementia changes character, makes Louise more irritable Jack F1</p> <p>Not all nerves firing Jack F1</p> <p>Hit and miss, more miss than hit Peter F2</p> <p>Reprioritising, Julia comes first and others come second; shift in construction of obligations to family Peter F2</p> <p>Objectification 'the shit'</p>	<p>Louise F1</p> <p>Loss of independence travelling Louise F1</p> <p>Belonging to place mediated through professional identity; disruption to sense of place Louise F1</p> <p>Become closer to Louise; wants her to be independent Jack F1</p> <p>Developed relationships with others experiencing YOD Peter F2</p> <p>Dementia-centric; moved from general social life to dementia-specific one. General activities can be confusing & disorientating Julia F2</p> <p>Support groups provide a new normal Julia F2</p> <p>Mastery of physical health/ tasks, finding triumphs in new places Julia F2</p> <p>Support groups not socio-economically diverse Julia F2</p> <p>Support groups great but difficult at first; forge new friendships, share</p>	<p>finances Julia F2</p> <p>More focus on future care needs/ wishes in wave three; disinclined to focus on future in earlier waves Julia, Peter F2</p> <p>Turning point: Shock of diagnosis, thought it was eye complaint, diagnosis delivered bluntly Julia F2</p> <p>Bad days: shuts herself down, enters own time and space Julia F2</p> <p>Intensifying the present; become more brave, going out to social activities more Julia F2</p> <p>Time of little importance to Julia; Peter is custodian of time Julia F2</p> <p>Busier since developing dementia Julia F2</p> <p>Made will; fear that sons will lose inheritance from grandmother if she dies first Francine F3</p> <p>Turning point: realised couldn't learn IT skills at work, glad to retire Francine F3</p>	<p>support groups Julia F2</p> <p>Selected people - don't have many but the ones we've got are quality Julia F2</p> <p>Embodied connections with brother and grandson Julia F2</p> <p>Got to know lots of people through support groups Peter F2</p> <p>Existing friendships becoming stronger, friends taking on more caring role for her and Peter Julia F2</p> <p>Worries about genetic transmission Julia F2</p> <p>Unable to control flow of knowledge - other people told without her permission Julia F2</p> <p>Fear that could be passed on genetically, hope that not Francine F3</p> <p>Information custodian, viewed as information resource, not shared everything, doesn't trust specialists Ron F3</p> <p>Developing new</p>	<p>Peter F2</p> <p>Increasing need for respite as Julia's condition deteriorates Peter F2</p> <p>Perceived pressure to accept 1-1 service Francine & Ron F3</p> <p>Greater variety of activities as year went on Francine & Ron F3</p> <p>Communication between carers and PWD of utmost importance Derek F4</p> <p>Wants services aimed at his own generation Derek F4</p>	
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	<p>Julia F2</p> <p>Entering a different world beyond normal but not 'madness'</p> <p>Julia F2</p> <p>Stress of seeing parents can cause bad days</p> <p>Julia F2</p> <p>Dementia contextualised in light of others' dementia: possibly both relief and fear Disclosure a relief Peter F2</p> <p>Role change to take on all domestic roles, struggles with bills & forms</p> <p>Peter F2</p> <p>Acutely observant of others' deterioration in support groups; Francine appears normal in comparison</p> <p>Francine & Ron F3</p> <p>Surrounds self with photos of family members to help her remember them, looks through photo albums</p> <p>Francine F3</p> <p>Accidents at home/ other mistakes ascribed to dementia</p> <p>Francine F3</p> <p>Fear of becoming like others with dementia in future</p> <p>Francine F3</p> <p>Worry that migraine medication may have</p>	<p>information, sociable</p> <p>Julia F2</p> <p>Accelerated intimacy</p> <p>Julia F2</p> <p>Immersion in dementia-centric activities</p> <p>Julia F2</p> <p>Immersion in dementia ID - WeightWatchers, watching TV programmes, developing new relationships, branching out into new activities</p> <p>Francine F3</p> <p>Unable to choose lost memories relates to identity as mother</p> <p>Francine F3</p> <p>Remembering bad things affects mental health and possibly creates barriers in fam relationships</p> <p>Francine F3</p> <p>Continually sorting out clothing like she did at work, perpetuating work identity in the home</p> <p>Francine F3</p> <p>Fear of making mistakes, loss of confidence, threat to identity as competent manager, employee</p> <p>Francine F3</p> <p>Fear of breaching own dress code leading to problems decision-making</p>	<p>Shock - seeing reduced brain size on scan</p> <p>Francine F3</p> <p>Fear of future and how she will be; uncertain of remaining time</p> <p>Francine, Ron F3</p>	<p>relationships at support groups</p> <p>Francine F3</p> <p>Strengthening existing friendships, going/ planning more holidays</p> <p>Francine F3</p> <p>Not being able to draw pictures - upsetting</p> <p>Francine F3</p> <p>No improvement in troubled relationship with younger sister</p> <p>Francine F3</p> <p>Problems happen more often than family know</p> <p>Ron F3</p> <p>Alert to signs of dementia</p> <p>Ron F3</p> <p>Changes from normalisation to minimising importance of memory in general</p> <p>Ron F3</p> <p>Trying to put things right, learning to cope together, trying to keep her engaged. She assumes invoking anger/ disapproval when not</p> <p>Ron F3</p> <p>Don't want to get to crisis point - no good for family</p> <p>Doreen F5</p> <p>Cheryl's brother 'sees what he wants to see'</p>		
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	<p>caused dementia, not wholly reassured Francine F3</p> <p>Writes messages to herself, stays close to Ron, bought car with larger speed display, revises road signs with Ron, cooks packet meals with instructions Francine F3</p> <p>Moderated shock of brain image over time Ron F3</p>	<p>Francine F3</p> <p>Feeling down, crying, worrying about physical health, distressed at emergence of dementia - forgetting names of colleagues Francine F3</p>		<p>Doreen F5</p> <p>'Outsider' perspective - aware of stress, different experience because lacks proximity Doreen F5</p>		
Children/ children's spouses	<p>She's too young. Powerless, nothing you can do Eliza F2</p> <p>Everyone experiences dementia differently Eliza F2</p> <p>Maintain normality, do normal things. Doesn't attend groups. Eliza F2</p> <p>Everyone experiences dementia differently David F3</p> <p>Dementia unfair in context of her life and other illnesses - things should balance out Laurence, David, William F3</p> <p>Don't attend support groups Laurence, David William F3</p> <p>Level of anxiety could be related to speed of progression</p>	<p>Doesn't go to support groups or contact YDUK Eliza F2</p> <p>Don't attend support groups although asked; not dementia-centric Laurence, David, William F3</p> <p>Want Francine to remain independent Laurence, David, William F3</p>	<p>Holidays scheduled, not spontaneous now Eliza F2</p> <p>Formalising wishes for future care so decisions already made in advance by Julia Eliza F2</p> <p>Need to occupy self when alone Marie, F3</p> <p>Structuring/ occupying time with variety of activities helps Annie F4</p> <p>Good days and bad days, unpredictability Annie F4</p> <p>Need to motivate her, structure her time and keep her occupied Craig F5</p> <p>Turning point: Mother</p>	<p>Jessica 'heartbroken' Louise F1</p> <p>Jessica experiences dementia differently as sees her less often Lauren F1</p> <p>Increased level of contact /support Eliza F2</p> <p>Take it day by day. Everyone's different with dementia, need to get Naomi involved so Peter can go out Eliza F2</p> <p>No sense of increased support Naomi/ Peter F2</p> <p>Shock but had had previous experience of serious health issue from husband Eliza F2</p> <p>Need to be strong, need</p>	<p>YDUK - helped with arranging respite, provided 1-1 support worker, negotiated access to day care; increased participation reduced isolation Annie F4</p> <p>Didn't have support for long time, YDUK godsend. Need services targeted at younger generation and individualised Annie F4</p> <p>Age of onset key to accessing services Cheryl F5</p> <p>Lack of information and support especially to make decisions Cheryl F5</p> <p>Day centre for younger people needed Craig F5</p>	<p>People wouldn't realise he had it because he's too young Annie F4</p> <p>General public think mum's behaviour is 'weird', it's embarrassing Cheryl F5</p> <p>Higher profile nationally, see more on TV. Focus is on finding cure but they need to focus more on day-to-day living with dementia Craig F5</p>

	<p>David, F3</p> <p>Boundaries between what is caused by dementia and what is normal forgetfulness David F3</p> <p>Protracted path to diag; relief not Lewy body Annie F4</p> <p>Relieved rediagnosed from Pick's to Alzheimer's, Pick's has shorter life expectancy Cheryl F5</p> <p>Practical strategies put in place but emotional impact harder to cope with; difficult to cope with temporal confusion Cheryl F5</p> <p>Cancer envy: person stays the same Cheryl F5</p>		<p>coming out of changing room in underwear Cheryl F5</p> <p>Turning point: Mother thinking her mother still alive Cheryl F5</p>	<p>time to get used to it, need to accept deterioration, she's too young Eliza F2</p> <p>Maintain normality, do normal things Eliza F2</p> <p>Looking for positives, approves of her engaging in activities. Carry on as normal, accept help when you want it Laurence F3</p> <p>Focus on present and on remaining abilities; normalises Laurence F3</p> <p>Don't be afraid to say something wrong to family Laurence F3</p> <p>Family as safe haven Marie F3</p> <p>Highlights effects of stress from family members. Didn't tell to worry less Marie F3</p> <p>Normalised to protect/ reduce anxiety David F3</p> <p>Increases importance of family, brings you closer together, less selfish Laurence F3</p> <p>Francine and Ron enjoying more time together, look</p>		
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				<p>for positives Laurence F3</p> <p>Keep dementia in the background. 1-1 might make her worse, more dependent David F3</p> <p>Approves of getting dog, stops her tidying David F3</p> <p>Being positive, having holidays, staying independent William F3</p> <p>Friends disappeared - they were drinking/ football watching buddies Annie F4</p> <p>Would euthanise if developed dementia - worse for family members who have to watch Annie F4</p> <p>Supporting him to live as much life as he can, supports to be independent Annie F4</p> <p>Muck in, get on with it Annie F4</p> <p>One branch of family don't get on with Annie F4</p> <p>Stress builds up, gets increasingly worse Craig F5</p>		
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				<p>Need for proximity, to be close by, keep her occupied Craig F5</p> <p>Strong family history of dementia, but didn't expect at that age Cheryl F5</p> <p>Understands mother's dementia in context of own accident and memory loss - realises what it must have been like for her family Cheryl F5</p> <p>Ambiguity of dementia - mum is/isn't there, is/isn't mum Cheryl F5</p> <p>Fear that she will develop dementia and her children will have to watch Cheryl F5</p> <p>Family seen as Craig, boys, Doreen, Mum Cheryl F5</p> <p>Brother doesn't understand, she has to do things Cheryl F5</p> <p>Mum's dementia causes tension between her and Craig Cheryl F5</p>		
Grandchildren	Invisibility of dementia compared to cancer Lauren F1	Support group enables grandparents to be with people who can understand		Proximity important, being there, sharing time and space Spatial administration		Compares invisibility of dementia compared to hair loss in cancer. Lauren F1

	<p>Knowing about dementia and being there - how might she be experiencing dementia and how could she help her? Lauren F1</p> <p>Limited awareness of dementia caused inappropriate reaction - regret Lauren F1</p>	<p>Lauren F1</p> <p>Personality change, Louise more sociable and humorous Transgenerationality Ontological insecurity Lauren F1</p> <p>Transition to fundraiser, using purpose and agency to defuse family tensions Lauren F1</p>		<p>Lauren F1</p> <p>Not school's business Lauren F1</p> <p>Friends more interested in Twitter Lauren F1</p> <p>Prefers stoic response to family illness Lauren F1</p> <p>Speaks to friends when common experience of a grandparent's illness Lauren F1</p> <p>Creates spaces to discuss with people not affected by dementia, beyond family boundaries Lauren F1</p> <p>Provides respite for granddad - perceives self as main supporter Lauren F1</p> <p>Family communication not regular apart from Jessica, sense of protecting each other Lauren F1</p> <p>Lack of shared memories disrupts reconstitution process/ symbolic construction of family. Have to suppress own emotions Lauren F1</p> <p>'Chosen family' - mother, Leo, Lucy, grandparents</p>		<p>General public might have misleading info. Lauren F1</p> <p>Should be taught about in schools Lauren F1</p>
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				<p>Lauren F1 Siblings don't know much about dementia Lauren F1</p> <p>Embodied connection with grandson Julia F2</p> <p>Grandson upset when told; knew dementia could cause her to forget him; he had noticed parents whispering about her; no more's been said Julia F2</p> <p>Went over granddaughter's head Julia F2</p> <p>Reduced visits from granddaughter - age-related Julia F2</p> <p>Doesn't expect help but accepts when offered Julia F2</p> <p>Grandchildren too young to notice Laurence F3</p> <p>Children had remarked on problems Francine had drawing David F3</p> <p>Older two children know William F3</p> <p>Son can get upset when Derek forgets to read a story</p>		
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				<p>Annie F4</p> <p>Sons noticed, younger one leaves conversation to adults, older one swamps with info and still expects her to answer</p> <p>Cheryl F5</p>		
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Appendix J: Conferences And Presentations

Conference	Date	Venue	Title/ format
Salford Postgraduate Annual Research Conference	June 2013	Salford University	Qualitative longitudinal research: its value, credibility and impact in an ever changing social world (Oral, co-presenter)
Families and Relationships Conference	May 2015	Edinburgh University	One family's experience of young onset dementia: a qualitative longitudinal exploration of relational transitions and continuities in the face of a progressive condition (Oral)
Salford Postgraduate Annual Research Conference	June 2015	Salford University	The family experience of young onset dementia (Poster)
Dementia and Human Rights Conference	September 2015	Salford University	Young onset dementia: a qualitative longitudinal exploration of evolving family experiences (Oral)
Dementia and Ageing Research Team	April 2016	Manchester University	Intergenerational experiences of young onset dementia: a qualitative longitudinal study (Oral)
Salford Postgraduate Annual Research Conference	June 2016	Salford University	Intergenerational experiences of young onset dementia: a qualitative longitudinal study (Three minute thesis)
<i>Forthcoming:</i> British Sociological Association Medical Sociology Conference	September 2016	Aston University	Experiencing young onset dementia in the family: A qualitative longitudinal case study of a 12 year old granddaughter (Oral)

Appendix K: Planned Publications

Topic	Co-authors	Target journal	Projected Submission Timeframe
Case study of Lauren's experiences	Supervisors	<i>Dementia</i>	November 2016
Write-up of the empirical research	Supervisors	<i>Sociology of Health and Illness</i>	February 2017
Impact of qualitative longitudinal findings on practice	Dementia charity/ Supervisors	<i>Journal of Dementia Care</i>	May 2017
Methodology paper	Supervisors	<i>Qualitative Health Research</i>	August 2017

Appendix L: National Centre for Research Methods blog post

Published 1st August 2016 (<http://bigqlr.ncrm.ac.uk/2016/08/01/guest-post-5-sue-bellass-the-challenges-of-multiple-perspectival-ql-analysis/>)

Our guest post today is by Sue Bellass, a PhD student in the School of Nursing, Midwifery, Social Work and Social Sciences at the University of Salford. Her thesis, which she is due to submit in August, has been exploring how intergenerational families are affected by young onset dementia over time.

In this post, Sue shares in detail her approach to analysing data over time, from multiple perspectives. The process has been complex and challenging, but has also brought creativity and freedom - and ultimately a deeper understanding of the lived experience of young onset dementia.

If you would like to know more about Sue's research, contact her by email: s.bellass@edu.salford.ac.uk.

The challenges of multiple perspectival qualitative longitudinal (QL) analysis: a strategy created for an intergenerational study of young onset dementia

Although dementia is often perceived to be a condition that occurs in later life, around 1 in 20 people with dementia are below the age of 65 (Alzheimer's Society, 2015). Over the last two decades there has been increasing interest in developing qualitative understandings of the experience of the condition in younger people; however, almost without exception existing studies have used cross-sectional designs, providing only a snapshot of life with an unpredictable, dynamic condition. For my PhD I decided to use a QL methodology to explore relationality over a twelve-month period by following five intergenerational families where one person had received a diagnosis of young onset dementia.

Since people with dementia are a marginalised, negatively positioned group (Sabat et al., 2011), I felt it was appropriate to democratise the research process to enable my participants to choose their preferred means of engaging with the study. This choice included the method of data collection (ethical approval was gained for interviews, audio/ video diaries, blogs and tweets) and, if participants opted for interviews, which family members would participate and where the interviews would take place. Ultimately, 18 participants chose to be interviewed, 16 of whom were interviewed in pairs or larger family groups, with two preferring individual interviews. Interviews were conducted in three waves at months 0, 6 and 12.

Analysing the data set has been a challenging process. As Henderson et al. (2012) note, despite increasing interest in QL methods, methods of analysing and representing complex QL data sets have rarely been explicated. I experienced this as a mixed blessing; on the one hand, there is space for creativity, flexibility and freedom, on the other, there is room for doubt to flourish! I have attempted to slice the data in different ways in order to interrogate the data set to best

effect. Inspired by Thomson (2010, 2014), I treated each family as a unique case and also aimed to create a cross-case analysis across the four generations represented in the families.

Initially I attempted to analyse the group interviews at the 'family' level, however it quickly became apparent that divergent accounts were being obscured. Subsequently I took a multiple perspectival approach (Ribbens McCarthy et al., 2003), teasing apart individual experiences within the families, viewing them as cases within a case. For each person, I induced categories of experience then, to permit holistic re-engagement, organised the raw data in a time-ordered matrix across the three waves.

Then, again for each person, I created a longitudinal matrix adapted from Saldana (2003) to look for transitions and continuities, using motif coding, a form of coding which draws attention to recurring elements in experiences, and describing through-lines, a crystallisation of a participant's change over time. Although it could be argued that such an approach may disguise intersubjective creation of meaning, I consciously retained a focus on relationality, creating spaces within the matrix to capture data on meaning-making processes over time. Finally I created an intergenerational matrix, organising the data by generation to look for patterns and themes, setting the data against the backdrop of the recent increasing public, policy and research interest in dementia to try and interweave biographical, generational and historical timescapes.

Qualitative research has faced criticism for lack of clarity regarding the relationship between theory and data, and this, I argue, is an important area to address as we continue to develop the contours of QL research. My own perspective has been influenced by Mills (1959), who describes a 'shuttle back and forth' between theory and data. I have utilised such an iterative approach, and have drawn on theory from the sociology of chronic illness and family and relationship sociology to develop understandings of the intergenerational experience of young onset dementia.

References:

Alzheimer's Society (2015). *Dementia 2015: Aiming higher to transform lives*. London: Alzheimer's Society.

Henderson, S., Holland, J., McGrellis, S., Sharpe, S., & Thomson, R. (2012). Storying qualitative longitudinal research: sequence, voice and motif. *Qualitative Research*, 12(1), 16-34.

Mills, C.W. (1959). *The sociological imagination*. London: Penguin.

Ribbens McCarthy, J., Holland, J., & Gillies, V. (2003). Multiple perspectives on the 'family' lives of young people: methodological and theoretical issues in case study research. *International Journal of Social Research Methodology*, 6(1), 1-23.

Sabat, S.R., Johnson, A., Swarbrick, C., & Keady, J. (2011). The 'demented other' or simply 'a person'? Extending the philosophical discourse of Naue and Kroll through the situated self. *Nursing Philosophy*, 12(4), 282-292.

Saldaña, J. (2003). *Longitudinal qualitative research: analyzing change through time*. California: Alta Mira Press.

Thomson, R. (2010). Creating family case histories: subjects, selves and family dynamics. In Thomson, R. (Ed.) *Intensity and insight: qualitative longitudinal methods as a route to the psycho-social*. Timescapes Working Paper Series No.3.

References

- Adam, B. (1990). *Time & Social Theory*. Cambridge: Polity.
- Adam, B. (2004). *Time*. Cambridge: Polity.
- Allen, J., Oyebode, J.R., & Allen, J. (2009). Having a father with young onset dementia: the impact on well-being of young people. *Dementia*, 8(4), 455-480.
- Allmark, P. (2002). The ethics of research with children. *Nurse Researcher*, 10(2), 7-19.
- Alzheimer's Disease International (2012). *World Alzheimer Report 2012: Overcoming the stigma of dementia*. London: Alzheimer's Disease International.
- Alzheimer's Disease International (2015). *World Alzheimer Report 2015: The global impact of dementia: an analysis of prevalence, incidence, causes and trends*. London: Alzheimer's Disease International.
- Alzheimer's Society (2015). *Dementia 2015: Aiming higher to transform lives*. London: Alzheimer's Society.
- Anthony, S., & Jack, S. (2009). Qualitative case study methodology in nursing research: an integrative review. *Journal of Advanced Nursing*, 65(6), 1171-1181.
- Arai, A., Matsumoto, T., Ikeda, M., & Arai, Y. (2007). Do family caregivers perceive more difficulty when they look after patients with early onset dementia compared to those with late onset dementia? *International Journal of Geriatric Psychiatry*, 22(12), 1255-1261.
- Årestedt, L., Persson, C., & Benzein, E. (2014). Living as a family in the midst of chronic illness. *Scandinavian Journal of Caring Sciences*, 28(1), 29-37.
- Åstedt-Kurki, P., & Hopia, H. (1996). The family interview: exploring experiences of family health and well-being. *Journal of Advanced Nursing*, 24(3), 506-511.
- Atkin, K., & Ahmad, W.I.U. (2001). Living a 'normal' life: young people coping with thalassaemia major or sickle cell disorder. *Social Science & Medicine*, 53(5), 615-626.

Bakker, C., de Vugt, M.E., Vernooij-Dassen, M., van Vliet, D., Verhey, F.R.J., & Koopmans, R.T.C.M. (2010). Needs in early onset dementia: a qualitative case from the NeedYD study. *American Journal of Alzheimer's Disease and Other Dementias*, 25(8), 634-640.

Bakker, C., de Vugt, M.E., van Vliet, D., Verhey, F.R.J., Pijnenburg, Y.A., Vernooij-Dassen, M.J.F.J., & Koopmans, R.C.T.M. (2012). The use of formal and informal care in early onset dementia: results from the NeedYD study. *American Journal of Geriatric Psychiatry*, 00, 1-9.

Balen, R., Blyth, E., Calabretto, H., Fraser, C., Horrocks, C. & Manby, M. (2006). Involving children in health and social research: 'human becomings' or 'active beings'? *Childhood*, 13(1), 29-48.

Bancroft, A. (2011). In the field: research relationships. In Jamieson, L., Simpson, R., & Lewis, R. (Eds.). *Researching families and relationships: reflections on process*. (pp. 71-83). Basingstoke: Palgrave Macmillan.

Barca, M.L., Thorsen, K., Engedal, K., Haugen, P.K., & Johannessen, A. (2014). Nobody asked me how I felt: experiences of adult children of persons with young-onset dementia. *International Psychogeriatrics*, 26(12), 1935-1944.

Barnard, M. (2005). Discomforting research: colliding moralities and looking for 'truth' in a study of parental drug problems. *Sociology of Health & Illness*, 27(1), 1-19.

Barnett-Page, E., & Thomas, J. (2009). Methods for the synthesis of qualitative research: a critical review. *National Centre for Research Methods Working Paper Series 01/09*, NCRM. Unpublished. Available at <http://eprints.ncrm.ac.uk/690/1/0109%2520Qualitative%2520synthesis%2520methods%2520paper%2520NCRM.pdf> (Accessed 5.12.13)

Bartlett, H., & Martin, W. (2002). Ethical issues in dementia care research. In Wilkinson, H. (Ed.) *The perspectives of people with dementia: research methods and motivations*. (pp.47-61). London: Jessica Kingsley.

Bartlett, R. (2012). Modifying the diary interview method to research the lives of people with dementia. *Qualitative Health Research*, 22(12), 1717-1726.

Bartlett, R. (2014). The emergent modes of dementia activism. *Ageing & Society*, 34(4), 623-644.

Baumgartner, L.M. (2007). The incorporation of the HIV/AIDS identity into the self over time. *Qualitative Health Research*, 17(7), 919-931.

Beard, R.L. (2004). In their voices: identity preservation and experiences of Alzheimer's disease. *Journal of Aging Studies*, 18(4), 415-428.

Beattie, A. M., Daker-White, G., Gilliard, J., & Means, R. (2002). Younger people in dementia care: a review of service needs, service provision and models of good practice. *Ageing & Mental Health*, 6(3), 205-212.

Beattie, A.M., Daker-White, G., Gilliard, J., & Means, R. (2004). 'How can they tell?' A qualitative study of the views of younger people about their dementia and dementia care services. *Health and Social Care in the Community*, 12(4), 359-368.

Bendelow, G. (1993). Pain perceptions, emotions and gender. *Sociology of Health & Illness*, 15(3), 273-294.

Bertaux, D., & Delacroix, C. (2000). Case histories of families and social processes: enriching sociology. In Chamberlayne, P., Bornat, J., & Wengraf, T. (Eds.). *The turn to biographical methods in the social sciences: comparative issues and examples*. (pp. 71-89). London: Routledge.

Biggerstaff, D.L., & Thompson, A.R. (2008). Interpretative Phenomenological Analysis (IPA): a qualitative methodology of choice in healthcare research. *Qualitative Research in Psychology*, 5(3), 173-183.

Bjørnholt, M., & Farstad, G.R. (2014). 'Am I rambling?' on the advantages of interviewing couples together. *Qualitative Research*, 14(1), 3-19.

Blaikie, N. (2007). *Approaches to social enquiry*. (2nd Ed.) Cambridge: Polity.

Blumer, H. (1969). *Symbolic Interactionism: perspective and method*. Berkeley: University of California Press.

Bond, J. (2001). Sociological perspectives. In Cantley, C. (Ed.). *A handbook of dementia care*. (pp. 44-61). Buckingham: Open University Press.

Bond, J., & Corner, L. (2001). Researching dementia: are there unique methodological challenges for health service research? *Ageing & Society*, 21, 95-116.

Bornat, J., & Bytheway, B. (2014). Grandparenting across the lifecourse. In Holland, J. & Edwards, R. (Eds.) *Understanding families over time: research & policy*. (pp. 176-193). Basingstoke: Palgrave Macmillan.

Boström, K., & Ahlström, G. (2004). Living with a chronic deteriorating disease: the trajectory with muscular dystrophy over ten years. *Disability & Rehabilitation*, 26(23), 1388-1398.

Bradbury-Jones, C., Taylor, J., & Herber, O. (2014). How theory is used and articulated in qualitative research: development of a new typology. *Social Science & Medicine*, 120, 135-141.

Brannen, J., Moss, P., & Mooney, A. (2004). *Working and caring in the twentieth century*. Basingstoke: Palgrave Macmillan.

Bray, L., Kirk, S., & Callery, P. (2014). Developing biographies: the experiences of children, young people and their parents of living with a long-term condition. *Sociology of Health & Illness*, 36(6), 823-839.

Buchholtz, M.B., Spiekermann, J., & Kächele, H. (2015). Rhythm and Blues – Amalie's 152nd session: From psychoanalysis to conversation and metaphor analysis – and back again. *The international Journal of Psychoanalysis*, 96(3), 877-910.

Burkitt, I. (1998). Bodies of knowledge: beyond Cartesian views of persons, selves and mind. *Journal for the Theory of Social Behaviour*, 28(1), 63-82.

Burkitt, I. (2008). *Social selves: theories of self and society*. (2nd Ed.). London: Sage.

Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health and Illness*, 4(2), 167-182.

- Bury, M. (1991). The sociology of chronic illness: a review of research and prospects. *Sociology of Health and Illness*, 13(4), 451-468.
- Bury, M., & Holme, A. (1991). *Life after ninety*. London: Routledge.
- Caddell, L.S., & Clare, L. (2010). The impact of dementia on self and identity: a systematic review. *Clinical Psychology Review*, 30(1), 113-126.
- Calhoun, C., Gerteis, J., Moody, J., Pfaff, S., & Virk, I. (2012) (Eds.). *Contemporary sociological theory*. (3rd ed.) Chichester: Wiley Blackwell.
- Cantley, C., Woodhouse, J., & Smith, M. (2005). *Listen to us: involving people with dementia in planning and developing services*. Northumbria: Dementia North.
- Carricaburu, D., & Pierret, J. (1995). From biographical disruption to biographical reinforcement: the case of HIV-positive men. *Sociology of Health & Illness*, 17(1), 65-88.
- Catthoor, K., Schrijvers, D., Hutsebaut, J., Feenstra, D., Persoons, P., De Hert, M., Peuskens, J., & Sabbe B. (2015). Associative stigma in family members of psychotic patients in Flanders: an exploratory study. *World Journal of Psychiatry*, 5(1), 118-125.
- Charmaz, K. (1983). Loss of self: a fundamental form of suffering in the chronically ill. *Sociology of Health and Illness*, 5(2), 168-195.
- Charmaz, K. (1990). 'Discovering' chronic illness: using grounded theory. *Social Science & Medicine*, 30(11), 1161-1172.
- Charmaz, K. (1991). *Good days, bad days: the self in chronic illness and time*. New Brunswick, New Jersey: Rutgers University Press.
- Charmaz, K. (1995). The body, identity and self: adapting to impairment. *The Sociological Quarterly*, 36(4), 657-680.
- Charmaz, K. (2002a). Stories and silences: disclosures and self in chronic illness. *Qualitative Inquiry*, 8, 302-328.
- Charmaz, K. (2002b). The self as habit: the reconstruction of the self in chronic illness. *The Occupational Therapy Journal of Research*, 22(1), S31-S41.

- Charon, J.M. (1998). *Symbolic Interactionism: an introduction, an interpretation, an integration*. (6th Ed.). New Jersey: Prentice-Hall.
- Chaston, D. (2011). Between a rock and a hard place: exploring the service needs of younger people with dementia. *Contemporary nurse*, 39(2), 130-139.
- Chattoo, S., Ahmad, W.I.U. (2008). The moral economy of selfhood and caring: negotiating boundaries of personal care as embodied moral practice. *Sociology of Health & Illness*, 30(4), 550-564.
- Chaudoir, S.R., Earnshaw, V.A., & Andel, S. (2013). "Discredited" versus "discreditable": understanding how shared and unique stigma mechanisms affect psychological and physical health disparities. *Basic and Applied Social Psychology*, 35(1), 75-87.
- Cheal, D. (1991). *Family and the state of theory*. Hertfordshire: Harvester Wheatsheaf.
- Chenail, R.J. (2010). Getting specific about qualitative research generalizability. *Journal of Ethnographic and Qualitative Research*, 5, 1-11
- Christensen, P., & Prout, A. (2002). Working with ethical symmetry in social research with children. *Childhood*, 9(4), 477-497.
- Clarke, C.L., & Keady, J. (2002). Getting down to brass tacks: a discussion of data collection with people with dementia. In Wilkinson, H. (Ed.) *The perspectives of people with dementia: research methods and motivations*. (pp. 25-46). London: Jessica Kingsley.
- Clarke-Steffen, L. (1997). Reconstructing reality: family strategies for managing childhood cancer. *Journal of Pediatric Nursing*, 12(5), 278-287.
- Clemerson, G., Walsh, S., & Isaac, C. (2014). Towards living well with young onset dementia: an exploration of coping from the perspective of those diagnosed. *Dementia*, 13(4), 451-466.
- Cohen, D., & Eisdorfer, C. (1986). *The loss of self: a family resource for care of Alzheimer's disease and related disorders*. New York: W.W.Norton.
- Conrad, P. (1990). Qualitative research on chronic illness: a commentary on method and conceptual development. *Social Science and Medicine*, 30(11), 1257-1263.

Conrad, P. & Barker, K.K. (2010). The social construction of illness: key insights and policy implications. *Journal of Health and Social Behaviour*, 51 (S), S67-S79.

Corbin, J. M., & Strauss, A. L. (2008). *Basics of qualitative research: techniques and procedures for developing grounded theory*. (3rd Ed.). Thousand Oaks, California: Sage.

Cotrell, V., & Schulz, R. (1993). The perspective of the patient with Alzheimer's Disease: a neglected dimension of dementia research. *The Gerontologist*, 33(2), 205-211.

Cowdell, F. (2006). Preserving personhood in dementia research: a literature review. *International Journal of Older People Nursing*, 1, 85-94.

Cox, S., & Keady, J. (Eds.) (1999). *Younger people with dementia: planning, practice and development*. London: Jessica Kingsley.

Crutch, S., Lehmann, M., Warrington, E., Warren, J., & Rohrer, J. (2012). The profile of language function in posterior cortical atrophy: not just a visual symptom. *Alzheimer's and Dementia: The Journal of the Alzheimer's Association*, 8(4), 740.

Cutcliffe, J.R. (2000). Methodological issues in grounded theory. *Journal of Advanced Nursing*, 31(6), 1476-1484.

Daly, K. (2002). Time, gender and the negotiation of family schedules. *Symbolic Interaction*, 25(3), 323-342.

Davies, R.R., Doran, M., & Lerner, A.J. (2011). Diagnosis and management of early onset dementia. *Progress in Neurology and Psychiatry*, 15(4), 12-16.

Davis, D.H.J. (2004). Dementia: sociological and philosophical constructions. *Social Science & Medicine*, 58, 369-378.

The Dementia Engagement and Empowerment Project (DEEP) guide (2014). Dementia words matter: guidelines on language about dementia. <http://dementiavoices.org.uk/wp-content/uploads/2015/03/DEEP-Guide-Language.pdf>

Delany, N., & Rosenvinge, H. (1995). Presenile dementia: sufferers, carers and services. *International Journal of Geriatric Psychiatry*, 10(7), 597-601.

Denzin, N.K. (1994). The art and politics of interpretation. In Denzin, N.K., & Lincoln, Y.S. (Eds.) *Handbook of qualitative research*. (pp. 500-515). California: Sage.

Department of Health (2009). *Living well with dementia: a national dementia strategy*. London: HMSO.

Department of Health, Cabinet Office & Prime Minister's Office, 10 Downing Street (2012). *Prime Minister's Challenge on Dementia*. London: HMSO.

Department of Health, Cabinet Office & Prime Minister's Office, 10 Downing Street (2015). *Prime Minister's Challenge on Dementia 2020*. London: HMSO.

Department of Health (2013). *Dementia: A state of the nation report on dementia care and support in England*. London: Department of Health.

Dewar, A. (2001). Protecting strategies used by sufferers of catastrophic illnesses and injuries. *Journal of Clinical Nursing*, 10(5), 600-608.

Dewing, J. (2007). A method for process consent with persons who have dementia. *Dementia*, 6(1), 11-25.

Dixon-Woods, M., Bonas, S., Booth, A., Jones, D.R., Miller, T., Sutton, A.J., Shaw, R.L., Smith, J.A., & Young, B. (2006). How can systematic reviews incorporate qualitative research? A critical perspective. *Qualitative Research*, 6(1), 27-44.

Doka, K. J. (1989). *Disenfranchised grief: recognising hidden sorrow*. Massachusetts: Lexington.

Ducharme, F., Kergoat, M-J., Antoine, P., Pasquier, F., & Coulombe, R. (2013). The unique experience of spouses in early-onset dementia. *American Journal of Alzheimer's Disease and Other Dementias*, published online. DOI: 10.1177/1533317513494443.

Edwards, R., & Gillies, V. (2012). Farewell to family? Notes on an argument for retaining the concept. *Families, Relationships and Societies*, 1(1), 63-69.

Eggenberger, S.K., & Nelms, T.P. (2007). Family interviews as a method for family research. *Journal of Advanced Nursing*, 58(3), 282-292.

Emiliani, F., Bertocchi, S., Potì, S., & Palareti, L. (2011). Process of normalization in families with children affected by hemophilia. *Qualitative Health Research*, 21(12), 1667-1678.

Etherington, K. (2004). *Becoming a reflexive researcher: using our selves in research*. London: Jessica Kingsley.

Faircloth, C.A., Boylstein, C., Rittman, M., Young, M.E., & Gubrium, J. (2004). Sudden illness and biographical flow in narratives of stroke recovery. *Sociology of Health & Illness*, 26(2), 242-261.

Family Law Reform Act (1987). London: The Stationery Office.

Farrall, S., Hunter, B., Sharpe, G., & Calverley, A. (2016). What 'works' when retracing sample members in a qualitative longitudinal study? *International Journal of Social Research Methodology*, 19(3), 287-300.

Finch, J. (1989). *Family obligations and social change*. Cambridge: Polity.

Finch, J. (2007). Displaying families. *Sociology*, 41(1), 65-81.

Finch, J., & Mason, J. (1993). *Negotiating family responsibilities*. London: Routledge.

Finfgeld-Connett, D. (2010). Generalizability and transferability of meta-synthesis research findings. *Journal of Advanced Nursing*, 66(2), 246-254.

Flynn, R., & Mulcahy, H. (2013). Early-onset dementia: the impact on family care-givers. *British Journal of Community Nursing*, 18(12), 589-605.

Forbat, L. (2003). Relationship difficulties in dementia care: a discursive analysis of two women's accounts. *Dementia*, 2(1), 67-84.

Forrest Keenan, K., Miedzybrodzka, Z., van Teijlingen, E., McKee, L., & Simpson, S.A. (2007). Young people's experiences of growing up in a family affected by Huntington's disease. *Clinical Genetics*, 71(2), 120-129.

Frazer, S.M., Oyebode, J.R., Cleary, A. (2012). How older women who live alone with dementia make sense of their experiences: an interpretative phenomenological analysis. *Dementia*, 11(5), 677-693.

French, J., & Swain, J. (1997). Changing disability research: participatory and emancipatory research with disabled people. *Physiotherapy*, 83(1), 26-32.

Freyne, A., Kidd, N., Coen, R., & Lawlor, B.A. (1999). Burden in carers of dementia patients: higher levels in carers of younger sufferers. *International Journal of Geriatric Psychiatry*, 14(9), 784-788.

Gabb, J. (2008). *Researching intimacy in families*. Basingstoke: Palgrave Macmillan.

Gabb, J. (2010). Home truths: ethical issues in family research. *Qualitative Research*, 10(4), 461-478.

Gallo, A.M., & Knafl, K. A. (1998). Parents' reports of "Tricks of the Trade" for managing childhood chronic illness. *Journal for Specialists in Paediatric Nursing*, 3(3), 93-100.

Gelman, C.R., & Greer, C. (2011). Young children in early-onset Alzheimer's disease families: research gaps and emerging service needs. *American Journal of Alzheimer's Disease and other Dementias*, 26(1), 29-35.

Gerhardt U. (1989). *Ideas about illness: an intellectual and political history of medical sociology*. Basingstoke: Macmillan Education.

Gerhardt, U. (1990). Qualitative research on chronic illness: the issue and the story. *Social Science & Medicine*, 30(11), 1149-1159.

Giddens, A. (1979). *Central problems in social theory: action, structure and contradiction in social analysis*. London: Macmillan.

Giddens, A. (1991). *Modernity and self-identity: self and society in the late modern age*. Cambridge: Polity.

Gilding, M. (2010). Reflexivity over and above convention: the new orthodoxy in the sociology of personal life, formerly sociology of the family. *The British Journal of Sociology*, 61(4), 757-777.

Gilliard, J., Means, R., Beattie, A., & Daker-White, G. (2005). Dementia care in England and the social model of disability: lessons and issues. *Dementia*, 4, 571-586.

Gillis, J. R. (1996). *A world of their own making: myth, ritual and the quest for family values*. Cambridge, Massachusetts: Harvard University Press.

Glaser, B.G., & Strauss, A.L. (1965). *Awareness of dying*. New York: Aldine.

Glaser, B.G., & Strauss, A.L. (1967). *The discovery of grounded theory: strategies for qualitative research*. New York: Aldine de Gruyter.

Glaser, B.G. & Strauss, A. L. (1975). *Chronic illness and the quality of life*. Saint Louis: CV Mosby Company.

Goffman, E. (1959). *The presentation of self in everyday life*. London: Penguin.

Goffman, E. (1961). *Asylums: essays on the social situation of mental patients and other inmates*. New York: Anchor Books.

Goffman, E. (1963). *Stigma: notes on the management of spoiled identity*. London: Penguin.

Green, J., & Thorogood, N. (2009). *Qualitative methods for health research*. (2nd Ed.) London: Sage.

Gregory, S. (2005). Living with chronic illness in the family setting. *Sociology of Health & Illness*, 27(3), 372-392.

Greicius, M.D., Geschwind, M.D., & Miller, B.L. (2002). Presenile dementia syndromes: an update on taxonomy and diagnosis. *Journal of Neurology, Neurosurgery and Psychiatry*, 72(6), 691-700.

Handberg, C., Thorne, S., Midtgaard, J., Vinther Nielsen, C., & Lomborg, K. (2015). Revisiting symbolic interactionism as a theoretical framework beyond the grounded theory tradition. *Qualitative Health Research*, 25(8), 1023-1032.

Harden, J. (2005). Parenting a young person with mental health problems: temporal disruption and reconstruction. *Sociology of Health & Illness*, 27(3), 351-371.

Harden, J., Backett-Milburn, K., Hill, M., & Maclean, A. (2010). Oh, what a tangled web we weave: experiences of doing 'multiple perspectives' research in families. *International Journal of Social Research Methodology*, 13(5), 441-452.

Harris, P.B. (2004). The perspective of younger people with dementia: still an overlooked population. *Social Work in Mental Health*, 2(4), 17-36.

Harris, P.B. (2013). Dementia and friendship: the quality and nature of the relationships that remain. *International Journal of Aging and Human Development*, 76(2), 141-164.

Harris, P.B., & Keady, J. (2009). Selfhood in younger onset dementia: transitions and testimonies. *Aging and Mental Health*, 13(3), 437-444.

Hart, N., & Crawford-Wright, A. (1999). Research as therapy, therapy as research: Ethical dilemma in new-paradigm research. *British Journal of Guidance & Counselling*, 27(2), 205-214.

Heaphy, B. (2007). *Late modernity and social change: reconstructing social and personal life*. London: Routledge.

Heaphy, B., & Davies, K. (2012). Critical friendships. *Families, Relationships and Societies*, 1(3), 311-326.

Hellström, I., Nolan, M., Nordenfelt, L., & Lundh, U. (2007). Ethical and methodological issues in interviewing persons with dementia. *Nursing Ethics*, 14(5), 608-619.

Henderson, J. (2001). "He's not my carer – he's my husband" : Personal and policy construction of care in mental health. *Journal of Social Work Practice*, 15(2), 149-159.

Henderson, S., Holland, J., McGrellis, S., Sharpe, S., & Thomson, R. (2012). Storying qualitative longitudinal research: sequence, voice and motif. *Qualitative Research*, 12(1), 16-34.

Henwood, K., & Coltart, C. (2012). Researching lives through time: analytics, narratives and the psychosocial. Timescapes Methods Guides Series, Guide no. 10, ESRC.

Heron, C. (1998). *Working with carers*. London: Jessica Kingsley.

- Hewitt, J.P. (1976). *Self and society: a symbolic interactionist social psychology*. Boston: Allyn and Bacon, Inc.
- Hicks, C. (1988). *Who cares: looking after people at home*. London: Virago.
- Hochschild, A. R. (1998). The sociology of emotion as a way of seeing. In Bendelow, G., & Williams, S.J. (Eds). *Emotions in social life: critical themes and contemporary issues*. (pp. 3-16) London: Routledge.
- Holdsworth, C., & Morgan, D. (2007). Revisiting the generalized other: an exploration. *Sociology*, 41(3), 401-417.
- Holland, J., & Edwards, R. (2014). *Understanding families over time: research and policy*. Basingstoke: Palgrave Macmillan.
- Horner, J., Heyman, A., Dawson, D., & Rogers, H. (1988). The relationship of aphasia to the severity of dementia in Alzheimer's disease. *Archives of Neurology*, 45(7), 760-763.
- Horner, S.D. (1998). Catching the asthma: family care for school-aged children with asthma. *Journal of Pediatric Nursing*, 13(6), 356-366.
- Hubbard, G., Downs, M.G., & Tester, S. (2003). Including older people with dementia in research: challenges and strategies. *Aging and Mental Health*, 7(5), 351-362.
- Hubbard, G., Kidd, L., & Kearney, N. (2010). Disrupted lives and threats to identity: the experiences of people with colorectal cancer within the first years following diagnosis. *Health*, 14(2), 131-146.
- Hughes, J.C., Louw, S.J., & Sabat, S.R. (2006). Seeing whole. In Hughes, J.C., Louw, S.J., & Sabat, S.R. (Eds.). *Dementia: mind, meaning and the person*. (pp. 1-39). Oxford: Oxford University Press.
- Hughes, K., & Emmel, N. (2012) Analysing time: times and timing in the lives of low-income grandparents. Timescapes Methods Guides Series, Guide no. 9, ESRC.
- Hurn, S. (2012). *Humans and other animals: cross-cultural perspectives on human-animal interactions*. London: Pluto.

- Hutchinson, K., Roberts, C., Kurrle, S., & Daly, M. (2014). The emotional well-being of young people having a parent with younger onset dementia. *Dementia*, published online, available at: <http://dem.sagepub.com/content/early/2014/04/24/1471301214532111>
- Inglis, T. (2010). Sociological forensics: illuminating the whole from the particular. *Sociology*, 44(3), 507-522.
- Irwin, S. (2013). Qualitative secondary data analysis: ethics, epistemology and context. *Progress in Development Studies*, 13(4), 295-306.
- Israel, M., & Hay, I. (2006). *Research ethics for social scientists*. London: Sage.
- Jamieson, L. (1998). *Intimacy: personal relationships in modern societies*. Cambridge: Polity.
- Jamieson, L., Simpson, R., & Lewis, R. (2011). (Eds.) *Researching families and relationships: reflections on process*. Basingstoke: Palgrave Macmillan.
- Jenkins, N. (2014). Dementia and the inter-embodied self. *Social Theory & Health*, 12(2), 125-137.
- Jenkins, N., Keyes, S., & Strange, L. (2016). Creating vignettes of early onset dementia: an exercise in public sociology. *Sociology*, 50(1), 77-92.
- Joachim, G., & Acorn, S. (2000). Stigma of visible and invisible conditions. *Journal of Advanced Nursing*, 32(1), 243-248.
- Johannessen, A., & Möller, A. (2011). Experiences of persons with early-onset dementia in everyday life: a qualitative study. *Dementia*, 12(4), 410-424.
- Johnson, M. (1999). Observations on positivism and pseudoscience in qualitative nursing research. *Journal of Advanced Nursing*, 30(1), 67-73.
- Johnson, P., & Duberley, J. (2000). *Understanding Management Research: an introduction to epistemology*. London: Sage.
- Jowsey, T., Ward, N.J., & Gardner, K. (2013). Agents in time: representations of chronic illness. *Health Sociology Review*, 22(3), 243-254.

Jutterström, L., Isaksson, U., Sandström, H., Hörnsten, A. (2012). Turning points in self-management of type 2 diabetes. *European Diabetes Nursing*, 9(2), 46-50b.

Kaiser, S., & Panegyres, P.K. (2007). The psychosocial impact of young onset dementia on spouses. *American Journal of Alzheimer's Disease and Other Disorders*, 21(6), 398-402.

Karner, T.X., & Bobbitt-Zeher, D. (2006). Losing selves: dementia care as disruption and transformation. *Symbolic Interaction*, 28(4), 549-570.

Killick, J. (1999). 'Dark head among the grey': experiencing the worlds of younger persons with dementia. In Cox, S., & Keady, J. (Eds.) *Younger people with dementia: planning, practice and development*. (pp. 153-172). London: Jessica Kingsley.

Kitwood, T. (1993) Person and process in dementia (Editorial). *International Journal of Geriatric Psychiatry*, 8, 541-545.

Kitwood, T. (1997). *Dementia reconsidered: the person comes first*. Buckingham: Open University Press.

Knafl, K., Breitmayer, B., Gallo, A., & Zoeller, L. (1996). Family response to childhood chronic illness: description of management styles. *Journal of Pediatric Nursing*, 11(5), 315-326.

Knalf, K.A., & Gilliss, C.L. (2002). Families and chronic illness: a synthesis of current research. *Journal of Family Nursing*, 8(3), 178-198.

Kontos, P.C. (2004). Ethnographic reflections on selfhood, embodiment and Alzheimer's disease. *Ageing and Society*, 24(6), 829-849.

Kralik, D., Koch, T., & Eastwood, S. (2003). The salience of the body: transition in sexual self-identity for women living with multiple sclerosis. *Journal of Advanced Nursing*, 42(1), 11-20.

La Fontaine, J., & Oyeboode, J.R. (2014). Family relationships and dementia: a synthesis of qualitative research including the person with dementia. *Ageing & Society*, 34(7), 1243-1272.

- Lambert, V., & Glacken, M. (2011). Engaging with children in research: theoretical and practical implications of negotiating informed consent/assent. *Nursing Ethics*, 18(6), 781-801.
- Larson, E. (1998). Reframing the meaning of disability to families: the embrace of paradox. *Social Science & Medicine*, 47(7), 865-875.
- Lawton, J. (2003). Lay experiences of health and illness: past research and future agendas. *Sociology of Health & Illness*, 25(3), 23-40.
- Leibrich, J. (1994). Improving the success rate in follow-up studies with former offenders. *Evaluation Review*, 18(5), 613-626.
- Liston, E. H. (1979). The clinical phenomenology of presenile dementia: a critical review of the literature. *Journal of Nervous and Mental Disease*, 167(6), 329-336.
- Lockeridge, S., & Simpson, J. (2013). The experience of caring for a partner with young onset dementia: how younger carers cope. *Dementia*, 12(5), 635-651.
- Locock, L., Ziebland, S., & Dumelow, C. (2009). Biographical disruption, abruption and repair in the context of Motor Neurone Disease, *Sociology of Health & Illness*, 31(7), 1043-1058.
- Luscombe, G., Brodaty, H., & Freeth, S. (1998). Younger people with dementia: diagnostic issues, effects on carers and use of services. *International Journal of Geriatric Psychiatry*, 13(5), 323-330.
- MacLean, A. and Harden, J. (2012) Generating group accounts with parents and children in qualitative longitudinal research: a practical and ethical guide. Timescapes Methods Guides Series, Guide no. 8, ESRC.
- Maines, D.R., Sugrue, N.M., Katovich, M.A. (1983). The sociological import of G.H.Mead's theory of the past. *American Sociological Review*, 48(2), 161-173.
- Maines, D.R. (2001). *The faultline of consciousness: a view of interactionism in sociology*. New York: Aldine de Gruyter.
- Mason, J. (2002). *Qualitative researching* (2nd Ed.). London: Sage.

Mason, J. (2008). Tangible affinities and the real life fascination of kinship. *Sociology*, 42(1), 29-45.

Mauthner, N.S., & Doucet, A. (2003). Reflexive accounts and accounts of reflexivity in qualitative data analysis. *Sociology*, 37(3), 413-431.

May, V. (2012). Are we really saying farewell to family? A response to Edwards and Gillie's 'Farewell to family?'. *Families, Relationships and Societies*, 1(3), 415-421.

May, V. (2013). *Connecting self to society: belonging in a changing world*. Basingstoke: Palgrave Macmillan.

May, V., & Muir, S. (2015). Everyday belonging and ageing: place and generational change. *Sociological Research Online*, 20(1),
<<http://www.socresonline.org.uk.salford.idm.oclc.org/20/1/8.html>>
DOI: 10.5153/sro.3555

May, V. (2016a). Belonging from afar: nostalgia, time and memory. *The Sociological Review*, DOI: <http://dx.doi.org/10.1111/1467-954X.12402>

May, V. (2016b). What does the duration of belonging tell us about the temporal self? *Time & Society*, 25(3), 634-651.

McKeown, J., Clarke, A., Ingleton, C., & Repper, J. (2010). Actively involving people with dementia in qualitative research. *Journal of Clinical Nursing*, 19(13-14), 1935-1943.

McKenna, H.P. (1997). Theory and research: a linkage to benefit practice. *International Journal of Nursing Studies*, 34(6), 431-437.

McKillop, J. (2002). Did research alter anything? In Wilkinson, H. (Ed.) *The perspectives of people with dementia: research methods and motivations*. (pp. 109-116). London: Jessica Kingsley.

McKillop, J., & Wilkinson, H. (2004). Make it easy on yourself! Advice to researchers from someone with dementia on being interviewed. *Dementia*, 3(2), 117-125.

McLeod, J. (2003). Why we interview now - reflexivity and perspective in a longitudinal study. *International Journal of Social Research Methodology*, 6(3), 201-211.

McLeod, J., & Thomson, R. (2009). *Researching social change: qualitative approaches*. London: Sage.

McNeill, T., Nicholas, D., Beaton, J., Montgomery, G., MacCulloch, R., Gearing, R., & Selkirk, E. (2014). The co-construction of couples' roles in parenting children with a chronic health condition. *Qualitative Health Research*, 24(8), 1114-1125.

Mead, G.H. (1932). *The philosophy of the present*. Illinois: The Open Court Publishing Company.

Mead, G.H. (1934). *Mind, self and society*. Chicago: University of Chicago Press.

Mendez, M., & Perryman, K. (2002). Posterior cortical atrophy: clinical characteristics and differences compared to Alzheimer's disease. *Dementia and Geriatric Cognitive Disorders*, 14(1), 33-40.

Mental Capacity Act (2005). Available online at <http://www.legislation.gov.uk/ukpga/2005/9/contents> (accessed 12 July 2013).

Miles, M.B., & Huberman, A.M. (1994). *Qualitative data analysis: an expanded sourcebook*. (2nd Ed.) California: Sage

Millenaar, J.K., van Vliet, D., Bakker, C., Vernooij-Dassen, M.J.F.J., Koopmans, R.C.T.M., Verhey, F.R.J., de Vugt, M.E. (2013). The experiences and needs of children living with a parent with young onset dementia: results from the NeedYD study. *International Psychogeriatrics*, published online, doi:10.1017/S1041610213001890.

Miller, T. (2015). Going back: 'stalking', talking and researcher responsibilities in qualitative longitudinal research. *International Journal of Social Research Methodology*, 18(3), 293-305.

Mills, C.W. (1959). *The sociological imagination*. London: Penguin.

Molyneaux, V., Butchard, S., Simpson, J., & Murray, C. (2011). Reconsidering the term 'carer': a critique of the universal adoption of the term 'carer'. *Ageing & Society*, 31(3), 422-437.

Monaghan, L. F., & Gabe, J. (2015). Chronic illness as biographical contingency? Young people's experiences of asthma. *Sociology of Health & Illness*, 37(8), 1236-1253.

Morgan, D.H.J. (1996). *Family connections: an introduction to family studies*. Cambridge: Polity.

Morgan, D.H.J. (2011). *Rethinking family practices*. Basingstoke: Palgrave Macmillan.

Muhlbauer, S. A. (2002). Navigating the storm of mental illness: phases in the family's journey. *Qualitative Health Research*, 12(8), 1076-1092.

Muraco, A., & Fredriksen-Goldsen, K.I. (2014). The highs and lows of caregiving for chronically ill lesbian, gay and bisexual elders. *Journal of Gerontological Social Work*, 57(2-4), 251-272.

National Health Service and Community Care Act (1990). Norwich: The Stationary Office.

National Institute for Clinical Excellence & Social Care Institute for Excellence (2006, updated 2016). *Dementia: supporting people with dementia and their carers in health and social care*. Clinical Guideline 42. London: NICE.

Neale, B. (2012) Qualitative longitudinal research: An introduction to the Timescapes Methods Guide Series. Timescapes Methods Guides Series, Guide no. 1, ESRC.

Neale, B., & Hanna, E. (2012) The ethics of researching lives qualitatively through time. Timescapes Methods Guides Series, Guide no. 11, ESRC.

Neale, B., Henwood, K. and Holland, J. (2012) Researching lives through time: an introduction to the Timescapes approach. *Qualitative Research*, 12(1), 4-15.

Neale, B., & Lau Clayton, C. (2014). Young parenthood and cross-generational relationships: The perspectives of young fathers. In Holland, J. & Edwards, R. (Eds.) *Understanding families over time: research & policy*. (pp. 69-87). Basingstoke: Palgrave Macmillan.

Neale, B. (2015). Time and the lifecourse: perspectives from qualitative longitudinal research. In Worth, N., & Hardill, I. (Eds.). *Researching the lifecourse: critical reflections from the social sciences*. (pp. 25-42). Bristol: Policy Press.

- Nettleton, S. (2006). *The sociology of health and illness*. (2nd ed.). Cambridge: Polity.
- Newens, A.J., Forster, P., & Kay, D.W.K. (1995). Dependency and community care in presenile Alzheimer's disease. *British Journal of Psychiatry*, 166(6), 777-782.
- Nicolaou, P.L., Egan, S.J., Gasson, N., & Kane, R.T. (2010). Identifying needs, burden and distress of carers of people with frontotemporal dementia compared to Alzheimer's disease. *Dementia*, published online, DOI: 10.1177/1471301209354024.
- Nind, M., Wiles, R., Bengry-Howell, A., & Crow, G. (2013). Methodological innovation and research ethics: forces in tension or forces in harmony? *Qualitative Research*, 13(6), 650-667.
- Norlyk, A., & Harder, I. (2010). What makes a phenomenological study phenomenological? An analysis of peer-reviewed empirical nursing studies. *Qualitative Health Research*, 20(3), 420-431.
- Notko, M., Jokinen, K., Malinen, K., Harju-Veijola, M., Kuronen, M., & Pirskanen, H. (2013). Encountering ethics in studying challenging family relations. *Families, Relationships and Societies*, 2(3), 395-408.
- Nott, P.N., & Fleminger, J.J. (1975). Presenile dementia: the difficulties of early diagnosis. *Acta Psychiatrica Scandinavica*, 51(3), 210-217.
- Nygård, L. (2006). How can we get access to the experiences of people with dementia? *Scandinavian Journal of Occupational Therapy*, 13, 101-112.
- O'Connor, D.L. (2007). Self-identifying as a caregiver: exploring the positioning process. *Journal of Aging Studies*, 21(2), 165-174.
- Olesen, V. (1994). Feminisms and models of qualitative research. In Denzin, N.K., & Lincoln, Y.S. (Eds). *Handbook of Qualitative Research*. (pp. 158-174). California: Sage.
- Oliver, M. (1983). *Social work with disabled people*. London: Macmillan.
- Oliver, P. (2010). *The student's guide to research ethics*. 2nd ed. Maidenhead: Open University Press.

- Orange, D. M. (2011). *The suffering stranger: hermeneutics for everyday clinical practice*. New York: Routledge/ Taylor & Francis Group.
- Oyebode, J.R., Bradley, P., & Allen, J.L. (2013). Relatives' experiences of frontal-variant frontotemporal dementia. *Qualitative Health Research*, 23(2), 156-166.
- Patrick, R. (2012). Recruiting & sustaining sample populations over time: possibilities and challenges. Timescapes Methods Guides Series, Guide no. 3, ESRC.
- Paterson, B.L. (2001). The shifting perspectives model of chronic illness. *Journal of Nursing Scholarship*, 33(1), 21-26.
- Paterson, B.L., Thorne, S.E., Canam, C., & Jillings, C. (2001). *Meta-study of qualitative health research: A practical guide to meta-analysis and meta-synthesis*. California: Sage.
- Pearlin, L.I., Mullan, J.T., Semple, S.J., & Skaff, M.M. (1990). Caregiving and the stress process: an overview of concepts and their measures. *The Gerontologist*, 30(5), 583-594.
- Pejlert, A. (2001). Being a parent of an adult son or daughter with severe mental illness receiving professional care: parents' narratives. *Health and Social Care in the Community*, 9(4), 194-204.
- Perlesz, A., & Lindsay, J. (2003). Methodological triangulation in researching families: making sense of dissonant data. *International Journal of Social Research Methodology*, 6(1), 25-40.
- Perry, J., & O'Connor, D. (2002). Preserving personhood: (re)membering the spouse with dementia. *Family Relations*, 51(1), 55-62.
- Pesonen, H-M., Remes, A. M., & Isola, A. (2011). Ethical aspects of researching subjective experiences in early-stage dementia. *Nursing Ethics*, 18(5), 651-661.
- Pipon-Young, F.E., Lee, K.M., Jones, F., & Guss, R. (2012). 'I'm not all gone, I can still speak: the experiences of younger people with dementia: an action research study. *Dementia*, 11(5), 597-616.
- Popay, J. (2003). Qualitative research and the epidemiological imagination: a vital relationship. *Gaceta Sanitaria*, 17(3), 58-63.

- Post, S.G. (2006). *Respectare*: moral respect for the lives of the deeply forgetful. In Hughes, J.C., Louw, S.J., & Sabat, S.R. (Eds.). *Dementia: mind, meaning and the person*. (pp. 223-234). Oxford: Oxford University Press.
- Pound, P., Gompertz, P., & Ebrahim, S. (1998). Illness in the context of older age: the case of stroke. *Sociology of Health & Illness*, 20(4), 489-506.
- Power, E.M. (2004). Toward understanding in postmodern interview analysis: interpreting the contradictory remarks of a research participant. *Qualitative Health Research*, 14(6), 858-865.
- Pratt, R. (2002). 'Nobody's ever asked how I felt.' In Wilkinson, H. (Ed.) *The perspectives of people with dementia: research methods and motivations*. (pp. 165-182). London: Jessica Kingsley.
- Prout, A., Hayes, L., & Gelder, L. (1999). Medicines and the maintenance of ordinariness in the household management of childhood asthma. *Sociology of Health & Illness*, 21(2), 137-162.
- Purves, B.A. (2010). Exploring positioning in Alzheimer Disease through analyses of family talk. *Dementia*, 10(1), 35-58.
- Rallison, L.B., & Raffin-Bouchal, S. (2013). Living in the in-between: families caring for a child with a progressive neurodegenerative illness. *Qualitative Health Research*, 23(2), 194-206.
- Ribbens McCarthy, J., Holland, J., & Gillies, V. (2003a). Multiple perspectives on the 'family' lives of young people: methodological and theoretical issues in case study research. *International Journal of Social Research Methodology*, 6(1), 1-23.
- Ribbens McCarthy, J., Edwards, R., & Gillies, V. (2003b). *Making families: moral tales of parenting and step-parenting*. Durham: sociology press.
- Ritzer, G., & Stepnisky, J. (2014). *Sociological theory*. (9th Ed.). Singapore: McGraw-Hill.

Roach, P., Keady, J., & Bee, P. (2011). 'It's easier just to separate them': practice constructions in the mental health care and support of younger people with dementia and their families. *Journal of Psychiatric and Mental Health Nursing*, 19(6), 555-562.

Roach P., Keady, J., Bee, P., & Hope, K. (2013). 'We can't keep going on like this': identifying family storylines in young onset dementia. *Ageing and Society*, Published online before print 16th April 2013, [accessed 20 April 2013].

Robinson, E. (2002). Should people with Alzheimer's Disease take part in research? In Wilkinson, H. (Ed.) *The perspectives of people with dementia: research methods and motivations*. (pp. 101-108). London: Jessica Kingsley.

Rolland, J.S. (1984). Towards a psychosocial typology of chronic and life-threatening illness. *Family Systems Medicine*, 2(3), 245-262.

Rolland, J. S. (1987). Chronic illness and the life cycle: a conceptual framework. *Family Process*, 26(2), 203-221.

Rosness, T.A., Haugen, P.K., & Engedal, K. (2008). Support to family carers of patients with frontotemporal dementia. *Aging & Mental Health*, 12(4), 462-466.

Rosness, T.A., Mjørud, M., & Engedal, K. (2011). Quality of life and depression in carers of patients with early onset dementia. *Aging & Mental Health*, 15(3), 299-306.

Sabat, S.R. (2005). Capacity for decision-making in Alzheimer's Disease: selfhood, positioning and semiotic people. *Australian and New Zealand Journal of Psychiatry*, 39(11-12), 1030-1035.

Sabat, S.R., & Harré, R. (1992). The construction and deconstruction of self in Alzheimer's disease. *Ageing and Society*, 12(4), 443-461.

Sabat, S.R., Johnson, A., Swarbrick, C., & Keady, J. (2011). The 'demented other' or simply 'a person'? Extending the philosophical discourse of Naue and Kroll through the situated self. *Nursing Philosophy*, 12(4), 282-292.

Saldaña, J. (2003). *Longitudinal qualitative research: analyzing change through time*. California: Alta Mira Press.

- Saldaña, J. (2013). *The coding manual for qualitative researchers*. (2nd Ed). Sage: Los Angeles.
- Sampson, E.L., Warren, J.D., & Rossor, M.N. (2004). Young onset dementia. *Postgraduate Medical Journal*, 80(941), 125- 139.
- Sandelowski, M., Docherty, S., & Emden, C. (1997). Qualitative metasynthesis: issues and techniques. *Research in Nursing and Health*, 20(4), 365-371.
- Sandelowski, M., & Barroso, J. (2003). Writing the proposal for a qualitative research methodology project. *Qualitative Health Research*, 13(6), 781-820.
- Sanders, C., Donovan, J., & Dieppe, P. (2002). The significance and consequences of having painful and disabled joints in older age: co-existing accounts of normal and disrupted biographies. *Sociology of Health & Illness*, 24(2), 227-253.
- Scambler, G., & Hopkins, A. (1988). Accommodating epilepsy in families. In Anderson, R., & Bury, M. (Eds.) *Living with chronic illness*. (pp. 156-176). London: Unwin Hyman.
- Schwandt, T.A. (1994) *Constructivist, interpretivist approaches to human inquiry*. In Denzin, N.K. & Lincoln, Y.S. (eds). *Handbook of Qualitative Research*. (pp. 118-137). California: Sage.
- Sharpe, L., & Curran, L. (2006). Understanding the process of adjustment to illness. *Social Science & Medicine*, 62(5), 1153-1166.
- Skaiff, M.M., & Pearlin, L.I. (1992). Caregiving: role engulfment and the loss of self. *The Gerontologist*, 32(5), 656-664.
- Smart, C. (2007). *Personal life: new directions in sociological thinking*. Cambridge: Polity.
- Smart, C. (2010). *Disciplined writing: on the problem of writing sociologically*. Realities Working Paper #13.
- Smart, C. (2011). Families, secrets and memories. *Sociology*, 45(4), 539-553.
- Smart, C., & Neale, B. (1999). *Family fragments?* Cambridge: Polity Press.

- Smart, C., Davies, K., Heaphy, B., & Mason, J. (2012). Difficult friendships and ontological security. *The Sociological Review*, 60(1), 91-109.
- Smith, A.P., & Kobayashi, K.M. (2002). Making sense of Alzheimer's disease in an intergenerational context: the case of a Japanese Canadian nisei (second-generation) headed family. *Dementia*, 1(2), 213-225.
- Smith, D.E. (1974). Women's perspective as a radical critique of sociology. *Sociological Inquiry*, 44(1), 7-13.
- Spencer, L., Ritchie, J., Lewis, J., & Dillon, L. (2003). *Quality in qualitative evaluation: a framework for assessing research evidence*. London: Government Chief Social Researcher's Office.
- Spencer, L., & Pahl, R. (2006). *Rethinking friendship: hidden solidarities today*. New Jersey: Princeton University Press.
- Sperlinger, D., & Furst, M. (1994). The services experiences of people with presenile dementia: a study of carers in one London borough. *International Journal of Geriatric Psychiatry*, 9(1), 47-50.
- Spirig, R. (2002). In invisibility and isolation: the experience of HIV-affected families in German-speaking Switzerland. *Qualitative Health Research*, 12(10), 1323- 1337.
- Stake, R.E. (1994). Case studies. In Denzin, N.K., & Lincoln, Y. S. (Eds.). *Handbook of Qualitative Research* (pp. 236-247). California: Sage.
- Stone, E., & Priestly, M. (1996). Parasites, pawns and partners: disability research and the role of non-disabled researchers. *British Journal of Sociology*, 47(4), 109-210.
- Suddaby, R. (2006). From the editors: what grounded theory is not. *Academy of Management Journal*, 49(4), 633-642.
- Svanberg, E., Stott, J., & Spector, A. (2010). 'Just helping': Children living with a parent with young onset dementia. *Aging and Mental Health*, 14(6), 740-751.

- Swain, J., Heyman, B., & Gillman, M. (1998). Public research, private concerns: ethical issues in the use of open-ended interviews with people who have learning difficulties. *Disability & Society*, 13(1), 21-36.
- Tee, S.R., & Lathlean, J.A. (2004). The ethics of conducting a co-operative inquiry with vulnerable people. *Journal of Advanced Nursing*, 47(5), 536-543.
- Telford, K., Kralik, D., & Koch, T. (2006). Acceptance and denial: implications for people adapting to chronic illness: literature review. *Journal of Advanced Nursing*, 55(4), 457-464.
- Thompson, P. (2005). Family myth, models and denials in the shaping of individual life paths. In Bertaux, D., & Thompson, P. (Eds.). *Between generations: family models, myths and memories*. (pp. 13-38). New Brunswick, New Jersey: Transaction Publishers.
- Thomson, R. (2007). The qualitative longitudinal case history: practical, methodological and ethical reflections. *Social Policy and Society*, 6(4), 571-582.
- Thomson, R. (2010). Creating family case histories: subjects, selves and family dynamics. In Thomson, R. (Ed.) *Intensity and insight: qualitative longitudinal methods as a route to the psycho-social*. Timescapes Working Paper Series No.3.
- Thomson, R. (2012) Qualitative methods as a route into the psycho-social. Timescapes Methods Guides Series, Guide no. 13, ESRC.
- Thomson, R. (2014a). Generational research: between historical and sociological imaginations. *International Journal of Social Research Methodology*, 17(2), 147-156.
- Thomson, R. (2014b). Expectations and realities: Motherhood and the female 'choice' biography. In Holland, J. & Edwards, R. (Eds.). *Understanding Families Over Time: Research and Policy*. (pp. 106-123). Basingstoke: Palgrave Macmillan.
- Thorne, S. E. (1999). The science of meaning in chronic illness. *International Journal of Nursing Studies*, 36(5), 397-404.

Thorne, S., Paterson, B., Acorn, S., Canam, C., Joachim, G., & Jillings, C. (2002). Chronic illness experience: insights from a metastudy. *Qualitative Health Research*, 12(4), 437-452.

Tolhurst, E., Bhattacharyya, S., & Kingston, P. (2012). Young onset dementia: The impact of emergent age-based factors upon personhood. *Dementia* published online before print August 17, 2012 (accessed 5 July 2013).

Tolhurst, E., & Kingston, P. (2013). Understanding the experience of dementia: utilising the theoretical insights of 'status passage'. *Social Theory & Health*, 11(2), 175-193.

Unger, P.K. (1990). *Identity, consciousness and value*. New York: Oxford University Press.

United Nations (1989). Convention on the Rights of the Child. Available online at <http://www.unicef.org/crc/> (accessed 17 July 2013).

Vieira, R.T., Caixeta, L., Machado, S., Silva, A.C., Nardi, A.E., Arias-Carrión, O., & Carta, M.G. (2013). Epidemiology of early-onset dementia: a review of the literature. *Clinical Practice and Epidemiology in Mental Health*, 9, 88-95.

Walsh, D., & Downe, S. (2005). Meta-synthesis method for qualitative research: a literature review. *Journal of Advanced Nursing*, 50(2), 204-211.

Ward-Griffin, C., Oudshoorn, A., Clark, K., & Bol, N. (2007). Mother-adult daughter relationships within dementia care: a critical analysis. *Journal of Family Nursing*, 13(1), 13-32.

Warin, J., Solomon, Y., & Lewis, C. (2007). Swapping stories: comparing plots: triangulating individual narratives within families. *International Journal of Social Research Methodology*, 10(2), 121-134.

Weingarten, K. (2013). "The cruel radiance of what is": helping couples live with chronic illness. *Family Process*, 52(1), 83-101.

White, J.M., & Klein, D.M. (2008). *Family theories*. (3rd Ed.) California: Sage.

Whyte, W.F. (1969). *Street corner society: the social structure of an Italian slum*. Chicago: University of Chicago Press.

Wilkinson, H. (2002). Including people with dementia in research: methods and motivations. In Wilkinson, H. (Ed.) *The perspectives of people with dementia: research methods and motivations*. (pp. 9-24). London: Jessica Kingsley.

Williams, C. (2000). Alert assistants in managing chronic illness: the case of mothers and teenage sons. *Sociology of Health & Illness*, 22(2), 254-272.

Williams, S. J. (2000). Chronic illness as biographical disruption or biographical disruption as chronic illness? Reflections on a core concept. *Sociology of Health & Illness*, 22(1), 40-67.

Williams, T., Dearden, A.M., & Cameron, I.H. (2001). From pillar to post - a study of younger people with dementia. *The Psychiatrist*, 25(10), 384-387.

Wilson, S. (2007). 'When you have children, you're obliged to live': motherhood, chronic illness and biographical disruption. *Sociology of Health & Illness*, 29(4), 610-626.

Wolf, B. M. (2015). Do families cope communally with breast cancer, or is it just talk? *Qualitative Health Research*, 25(3), 320-335.

Wong, P.P., & Tomer, A. (2011). Beyond terror and denial: the positive psychology of death acceptance. *Death Studies*, 35(2), 99-106.

World Health Organisation (2010). *International Statistical Classification of Diseases and Health-Related Problems 10th Revision*. Available at <http://apps.who.int/classifications/icd10/browse/2010/en>

World Health Organisation (2012). *Dementia: a public health priority*. Switzerland: World Health Organisation.

Wu, H-L., & Volker, D.L. (2009). The use of theory in qualitative approaches to research: application in end-of-life studies. *Journal of Advanced Nursing*, 65(12), 2719-2732.

Young, B., Dixon-Woods, M., Findlay, M., & Heney, D. (2002). Parenting in a crisis: conceptualising mothers of children with cancer. *Social Science & Medicine*, 55(10), 1835-1847.

Zhao, S. (1996). The beginning of the end or the end of the beginning? The theory construction movement revisited. *Sociological Forum*, 11(2), 305-318.